Experience of diagnosis, information and support needs of women diagnosed with ductal carcinoma in situ (DCIS)

Focus group interviews

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Acknowledgments

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# Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acknowledgements</td>
<td>i</td>
</tr>
<tr>
<td>Executive summary</td>
<td>1</td>
</tr>
<tr>
<td>1 Background</td>
<td>3</td>
</tr>
<tr>
<td>1.1 Literature review</td>
<td>3</td>
</tr>
<tr>
<td>2 Research method</td>
<td>9</td>
</tr>
<tr>
<td>2.1 Introduction</td>
<td>9</td>
</tr>
<tr>
<td>2.2 Aims of the focus group interviews</td>
<td>9</td>
</tr>
<tr>
<td>2.3 Research design</td>
<td>10</td>
</tr>
<tr>
<td>2.4 Participants</td>
<td>11</td>
</tr>
<tr>
<td>2.5 Data collection</td>
<td>11</td>
</tr>
<tr>
<td>2.6 Data analysis</td>
<td>13</td>
</tr>
<tr>
<td>2.7 Ethical considerations</td>
<td>13</td>
</tr>
<tr>
<td>2.8 Limitations of methods</td>
<td>15</td>
</tr>
<tr>
<td>3 Findings from the focus group interviews</td>
<td>17</td>
</tr>
<tr>
<td>3.1 Profile of participants</td>
<td>17</td>
</tr>
<tr>
<td>3.2 The needs of women diagnosed with ductal carcinoma in situ: an introduction</td>
<td>22</td>
</tr>
<tr>
<td>3.3 Experience of diagnosis</td>
<td>23</td>
</tr>
<tr>
<td>3.4 Information needs</td>
<td>30</td>
</tr>
<tr>
<td>3.5 Support needs</td>
<td>35</td>
</tr>
<tr>
<td>3.6 Adjusting to the diagnosis</td>
<td>41</td>
</tr>
<tr>
<td>3.7 Summary of findings</td>
<td>42</td>
</tr>
</tbody>
</table>
### Contents contd.

| 4 | The needs of women diagnosed with DCIS | 48 |
|  | 4.1 Discussion | 48 |
|  | 4.2 Conclusion | 51 |
|  | 4.3 Recommendations | 51 |

### Tables

| 1 | Age profile of DCIS population in Victoria in 1996 | 21 |
| 2 | Categories and sub-categories extracted from focus group interviews with women diagnosed with DCIS | 23 |
| 3 | Summary of findings from focus group interviews with women diagnosed with DCIS | 43 |

### Figures

| 1 | Side view of breast | 3 |
| 2 | Age profile of participants in the focus group interviews | 17 |
| 3 | Residential profile of participants in the focus group interviews | 18 |
| 4 | Education level of participants in the focus group interviews | 18 |
| 5 | Employment status of participants in the focus group interviews | 19 |
| 6 | Length of time since diagnosis of participants in the focus group interviews | 19 |
| 7 | Age profile of participants in the focus group interviews | 21 |
| 8 | Age profile of DCIS population, from BreastScreen Victoria 1996 data | 22 |
Experience of diagnosis, information and support needs of women diagnosed with ductal carcinoma in situ (DCIS)
Executive summary

This report presents the findings of a qualitative study in New South Wales (NSW) that explored the needs of women diagnosed with ductal carcinoma in situ (DCIS). Participants included women diagnosed with DCIS, recruited via selected clinicians. Data was collected through focus group interviews. The women's major needs were related to: their experience of diagnosis; their informational needs; their support needs; and their adjustment to their diagnosis.

This study highlighted the confusion that may surround a diagnosis of DCIS, and the lack of information given to women about DCIS and its prognosis.

This project highlights: the value of qualitative research in facilitating in-depth exploration of participants' experiences, and in exploring areas of limited knowledge or great complexity.

In spite of the small sample size, the findings of this project highlight the need for:

- Informing health professionals about women's confusion about the terms ‘DCIS’, ‘ductal carcinoma in situ’ and ‘carcinoma’, and the effect of these terms on women's interpretation of the nature of the disease and their consequent emotional state.
- Keeping health professionals informed about the current research concerning DCIS via the development and dissemination of clinical practice guidelines relating to the management of DCIS.
- Clear communication from health professionals to women about the nature of DCIS, the current research about its prognosis and available treatment options.
- The development of comprehensible and comprehensive consumer resources about DCIS.
- Making appropriate support available to women diagnosed with DCIS within the Breast Cancer Support Service (BCSS).
- Making support groups available to women diagnosed with DCIS, in both rural and urban areas.
These recommendations are in keeping with the recently published NHMRC National Breast Cancer Centre Psychosocial clinical practice guidelines: providing information, support and counselling for women with breast cancer (1999). The guidelines state that appropriate, detailed information promotes understanding and increases the psychological well-being of women with breast cancer, and that allowing women the opportunity to discuss their feelings with a member of the treatment team or counsellor decreases their psychological distress. Many of the guideline recommendations are based on meta-analyses and randomised, controlled trials.

Recommendations for future research include:

- Conducting a larger, national, qualitative study using a representative sample, which includes women from rural, Non-English Speaking Background (NESB) and Aboriginal and Torres Strait Islander backgrounds, to assess the generalisability of the key findings from this study.

- Conducting a large, quantitative study at a later stage, when wider education about the nature of DCIS among women and health professionals has been achieved through the development and dissemination of consumer resources specific to DCIS and clinical practice guidelines for the management of DCIS. A quantitative approach would be of greater benefit at a time when the issue of DCIS is no longer regarded as so complex. The aim of a large quantitative study would be to assess the needs and concerns of women diagnosed with DCIS and to compare these needs and concerns to women diagnosed with breast cancer.
1 Background

1.1 Literature review

This literature review aims to present a brief overview of the key published and unpublished literature about the diagnosis, incidence, prevalence, natural history and treatment of DCIS. It also explores the published and unpublished literature concerning women's understanding of the nature of DCIS and their psychosocial, physical and practical needs.

1.1.1 What is ductal carcinoma in situ?

Ductal carcinoma in situ (DCIS) is a non-invasive variant of breast cancer and is defined as a proliferation of malignant duct epithelial cells without light microscopic evidence of invasion into the periductal stroma.1 See figure 1.

Figure 1

![Figure 1](image)

Until recently, DCIS was a relatively uncommon disease, representing only about 2% of all newly diagnosed cases of breast cancer.8 In the past a palpable mass or a nipple discharge was the most common presentation of DCIS. During the past decade, as mammography has become technically better and more widely available – with the National Program for the Early Detection of Breast Cancer (NPEDBC) in 1990, for example – the number of new cases of DCIS has increased dramatically. In fact, in recent years DCIS has come to be perceived as a “disease of screening” with most DCIS lesions in the 1990s presenting as clinically
occult microcalcifications on screening mammography. It has been estimated that DCIS now accounts for 10-40% of lesions detected by mammographic screening in Australia, and 4-10% of breast malignancies in men. The NSW Breast Cancer Institute recently reported that of the 1090 women with cancer identified in the BreastScreen NSW Program during 1996, 173 had DCIS alone (with no invasive component), representing 15.9% of all screen-detected breast cancers in NSW. DCIS was estimated to represent 17% of all new breast cancer diagnoses in the USA during 1997.

The notion of DCIS as a single disease has evaporated. It is now well recognised as a heterogeneous group of lesions with a diverse malignant potential. As understanding of the disease has evolved and the range of treatment options has widened, the process of making decisions about management has become more complex and more controversial. Consequently the first textbook devoted solely to the disease was not published until 1997.

One of the current dilemmas is that the natural history of DCIS is unknown. The link between DCIS and invasive breast cancer is not entirely clear, but given that almost all cases diagnosed have been treated, it has been estimated that 20-25% of DCIS lesions will progress to invasive breast cancer. It must be noted that these figures were obtained from very small studies of patients treated with biopsy only. However, it is not known which factors predict for the progression of DCIS to invasive cancer. It appears that the histopathological subtypes of DCIS influence the probability of local recurrence of DCIS and the development of invasive disease. At present there are several classifications of DCIS based on histological structure, but no international consensus.

The most innocuous, low grade-looking forms of DCIS may never cause a clinical problem if left untreated. This has led Foucar, an American pathologist, and others to question the use of the term “carcinoma”. They suggest that the very term may affect patient morbidity and physicians' choice of therapy for the disease. “One problem is in the very name of these things as cancer. Once patients hear that word “cancer”, what they envision is metastatic disease, and it’s difficult to get beyond that to the idea that you are talking about the risk of future cancer.” On the other hand, the most aggressive, high-grade forms of DCIS are much more likely to develop into invasive cancer if untreated, and in considerably shorter periods of time.
For years, the standard treatment for most patients with DCIS has been mastectomy. Although mastectomy is being seen as overtreatment for many cases, it has resulted in an extremely low local recurrence rate and extremely low mortality from breast cancer.\textsuperscript{xvii, xviii} Mastectomy is associated with a 98-100\% survival rate and subsequent recurrence of invasive cancer in the chest wall of 0-5\%.\textsuperscript{xix} Conservative surgery alone is associated with a local recurrence rate of 20\%, and half of these recurrences (10\% overall) are invasive, with a potential long-term cure rate of at least 90\%. The addition of radiotherapy reduces the risk of local recurrence to 10\%, and half of these recurrences (5\% overall) are invasive, with a potential long-term cure rate of 95\%.\textsuperscript{xx} It is generally recommended that dissection of the axillary nodes is unnecessary in most women with DCIS.\textsuperscript{xx} In the past decade there has been considerable interest in breast conserving surgery for patients. A number of prospective randomised trials evaluating breast preservation are in progress in Europe, including the European Organisation for Research and Treatment of Cancer Trial and the UK trial (which includes a Tamoxifen arm). One prospective randomised trial has been published, Protocol B-17, conducted by the National Surgical Adjuvant Breast Project in the United States.\textsuperscript{xxx}

1.1.2 Previous research about the needs of women diagnosed with DCIS

Only two articles specifically dealing with the needs of women with DCIS were found in the review of the literature. These articles will be critically appraised using the approach recomended by Trisha Greenhalgh and the British Medical Journal review on qualitative research.\textsuperscript{xvii, xviii} It must be noted that “the critical appraisal of qualitative research is a relatively underdeveloped science and the questions posed are still being refined”.\textsuperscript{31}

The first study was small and descriptive using qualitative methods to explore women’s experiences of DCIS and “to attempt to identify whether women having this condition appeared to have common or different responses from those having invasive breast cancer”.\textsuperscript{xviii} Interviews were conducted with convenience sample of 10 women diagnosed with DCIS and treated at two hospitals in an Australian State capital city. Three themes emerged from these interviews: discovering the problem; reaction to the diagnosis; and information. The researchers found that most women reacted in a calm and accepting way to receiving the diagnosis of DCIS; that women perceived information-giving as deficient; and that none of the
women knew they had a non-invasive condition, with one women thinking that she had a benign condition and another that her disease was “evasive”.

The qualitative approach of the first study was appropriate to the primary research question of this project, that is, to explore women's experiences of DCIS, given the lack of previous research in this area. However, the study was limited by its use of a convenience sample, which means the results only report the experiences of these 10 women and are not generalisable. The study was also limited by its omission of socioeconomic measures such as employment, education, ethnicity of the sample, and range of ages; and by its failure to identify the capital city in which the research took place.

Secondly, the researchers potentially created bias in the study by the interviewer's acknowledgement during the interviews that she had also been treated for DCIS and discussion of her own experiences of DCIS and other personal issues. Furthermore, the interviewer explained the “real nature” of DCIS to those women who thought they had cancer, which not only changed the role of the interviewer but may also have influenced what women reported about their experiences and concerns.

Thirdly, the researchers did not explain in detail the outline of the interview. For example, they failed to report whether an interview protocol was used, the duration of the interviews and how the interviewer would allow women to discuss other issues of interest.

Fourthly, the method of analysis of the qualitative data was not described in detail. The approaches used to maintain rigour were not described. Lastly, the study does not, and within the existing methodology cannot answer the secondary question proposed – that is, to identify whether women diagnosed with DCIS appeared to have common or different responses from those diagnosed with invasive breast cancer. There is a cursory comparison of women's experiences with DCIS compared to those with breast cancer, using the past literature on the subject. To address this question optimally the study would need to survey women in both the DCIS and breast cancer population, using the same validated survey instrument or interview protocol to assess their perceptions of their experiences and concerns.
The second study located in the literature search was a case study of a 47 year-old women diagnosed with DCIS.\textsuperscript{xiii} This study discussed the evaluation and management of a woman who decided after considerable discussion to undergo bilateral mastectomy. Some areas highlighted by the case study were: the effect of the woman's family history of breast cancer on her decision, that is, the woman's mother had died of breast cancer; and the fears the woman had about radiation treatment, losing her breast, and invasive cancer, even though she had been told that it was a precancerous condition. The woman was reported as saying "it's a question of semantics, what you call it. These are actually cancer cells", "I was so afraid that I had invasive cancer". In a follow-up note a year later the woman was happy about her decision but was having difficulty adjusting to her physical appearance and was still concerned about having a recurrence.\textsuperscript{xiii} This study discussed one woman's perception of being diagnosed with DCIS. Further research would be needed to explore whether her experiences are generalisable to the larger DCIS population.

1.1.3 Women's experiences of DCIS trials

Two studies, concerning patients' viewpoints of DCIS trials were found. Both studies were discussion papers by a patient who had refused participation in the UK Randomised Controlled Trial for the Management of Screen-Detected Ductal Carcinoma In Situ (DCIS) of the Breast in 1991.\textsuperscript{xxvi,xxvii} The patient refused participation in the trial because she wanted to know her physician's preferred treatment of choice or, at the very least, to be given an explanation of all the treatment options available to her: "my worries about the unbalanced and excessive treatment options for a non-invasive cancer were exacerbated by my research findings, leading me to the sad conclusion that 'informed consent' was impossible [in the trial]". She felt that "when most in need of support I was sent away to inform myself, feeling isolated from the medical team who seemed at that moment to be a research team more interested in future generations than in my own plight". She commented on a study that reported that only 25% of patients with DCIS will progress to invasive cancer, and that there is general uncertainty about the natural history of the disease, and felt that this could mean that participation in a trial may result in a substantial level of overtreatment for some women. She believes that "technological and ethical examination of multi-centre trials by a national committee" are needed and that the question that should be posed to researchers
is “How can we achieve a partnership so that patient care and research and development make progress?”. Further research is needed to ascertain whether this patient's viewpoint about DCIS trials is generalisable to the larger DCIS population.

1.1.4 Why use a qualitative approach?

As highlighted in the literature review there is a significant lack of research concerning the needs of women diagnosed with DCIS. Qualitative research approaches facilitate in depth exploration of experiences, in this case, women's experiences of DCIS. Qualitative research is an appropriate methodology in areas where there is limited knowledge to generate guidelines and services.

Data collection in this study was through focus group interviews. A focus group may be defined as a group interview or a group discussion where the focus is on a particular topic of interest – usually a health problem or a response to a situation or issue. The group is also often focussed in the sense that the participants often share some essential characteristic, such as a health problem, or the participants are of similar age or ethnic background. Focus groups capitalise on communication between participants in order to generate data. Participants are encouraged to talk to one another – asking questions, exchanging anecdotes and commenting on each others' experiences and points of view. Focus groups are not intended to achieve consensus but to examine the range of different attitudes towards an issue or problem.

Although focus group methodology has its roots in market research work, it has also been an integral part of ethnographic research in anthropology. Over the past decade there has been increasing interest among health service and public health researchers in the combined use of qualitative and quantitative methods.
2 Research Method

2.1 Introduction

Given the increased detection of ductal carcinoma in situ (DCIS) and the paucity to date of research concerning the needs of women diagnosed with DCIS, this study explores women's experiences of being diagnosed with DCIS and their psychosocial, practical and physical needs. An explorative descriptive research design was used and data collection was through focus group interviews.

2.2 Aims of the research

The research aims to explore in depth women's experiences of their diagnosis and treatment of DCIS and to provide information to assist in the development of a valid and reliable survey instrument for assessing the psychosocial, practical and physical needs of women diagnosed with DCIS in the following areas:

1. Women's understanding of their diagnosis
2. Women's information needs
3. Women's perceptions of their involvement in decisions about treatment
4. Women's perceptions of their involvement in clinical trials
5. Women's psychosocial support needs during diagnosis & treatment
6. Women's physical support needs during diagnosis & treatment
7. Women's practical support needs during diagnosis & treatment
8. Recommendations that women would give other women newly diagnosed with DCIS
9. Other issues raised in the discussions
2.3 Research Design

Participants for five focus group interviews were recruited from clinicians in NSW selected in consultation with the NHMRC National Breast Cancer Centre (NBCC). Fifteen selected surgeons and radiation oncologists were selected to participate in the study due to their interest in breast cancer and their involvement in the treatment of women diagnosed with DCIS. The surgeons and radiation oncologists were sent an information letter explaining the purpose of the study, describing the focus group interviews and providing a contact for more information, with a reply form and reply paid envelope for clinicians to indicate whether or not they would be willing to be involved in selecting women for the focus group interviews. To increase the response rate those clinicians who had not replied within two weeks were telephoned and asked to confirm whether they were willing to participate in the study. Seven clinicians, including both surgeons and radiation oncologists, agreed to be involved in the study.

Clinicians then sent eligible women an information letter from the NBCC which explained the purpose of the study and described the focus group interviews, a response form, a consent form and a reply paid envelope to indicate whether or not they would be willing to be contacted about the study and which group they would prefer to attend. Each clinician sent letters to a consecutive sample of five women who had most recently been diagnosed with DCIS. Women were excluded from the study if they were diagnosed less than six months prior to the study, spoke poor English or were considered by their surgeon/oncologist to be too ill to participate.

Women who indicated on the reply form that they would like to take part in the study were contacted to confirm their willingness to participate in the focus group interviews, and so any questions they had about the study could be answered. Of the 35 women selected, 26 agreed to participate. All 26 women were then sent a letter explaining where and when to attend, and contacted the day before to remind them of the appointment. Five to six women attended each focus group.

The response rate of the focus group interviews was thus calculated to be 74%.
2.4 Participants

Women were considered eligible to participate in the focus group interviews if:

- they had DCIS confirmed histopathologically (that is, an abnormal proliferation of duct epithelial cells without light microscopic evidence of invasion into the periductal stroma.)\(^1\)
- they received their diagnosis at least 6 months prior to the study
- they spoke and understood English well enough to participate in the focus group interviews
- they were not considered by their surgeon/oncologist to be too ill to participate

2.5 Data collection

Five focus group interviews were conducted, of two hours each. Each woman attending the urban focus group interviews received $25 as compensation for travelling expenses incurred. In the rural focus group women were compensated for their travelling expenses according to distance travelled. Light refreshments were also provided.

The focus group interviews were held in locations that were thought to be most convenient and known to the women. Two groups were held in Westmead Hospital (one in the morning and one in the evening so working women could also attend), one group was held in the YWCA in the city, one in Liverpool Hospital and one in Orange so a rural perspective could be obtained. The groups all took place between 1 July 1998 and 31 July 1998.

All the focus group interviews were audio-taped to optimise the accuracy of data collection. In the metropolitan focus group interviews, a research assistant took notes and raised relevant questions that did not arise naturally from the discussions. A review of the audio-tapes of the metropolitan focus group interviews revealed that this did not add to data collection, so a research assistant did not play this role in the rural focus group interviews. All the focus groups were facilitated by the principal researcher. All the women gave verbal consent for the sessions to be audio-taped, and were assured that the audio-tapes would only be available for transcribing purposes. The ethics of the group discussion were explained and women wore their first names only on a badge.
Ground rules for participation in the group included:

- participants did not have to talk about anything that they did not feel comfortable with
- participants were free to leave the group at any time
- participants would speak one at a time
- participants would recognise that all responses are valuable and that there are no right or wrong responses
- participants would avoid being judgmental about anyone else
- participants would respect group confidentiality

To run the focus group the facilitator:

- introduced herself, the project and the topic for discussion
- defined the purpose of the group
- established the group rules of the discussion
- clarified who would use the results and how they would be used
- explained the procedure for the discussion
- created an environment conducive to open discussion
- nurtured different perceptions and points of view without coercion
- avoided being judgmental
- observed body language
- avoided conflicts and mediated conflicts if that arose
- kept the session on time
- took notes and recorded the discussion

A discussion guide was developed for the focus group interviews by the facilitators, with reference to the BMJ review on qualitative research and comments from key medical, behavioural science and counselling staff at the NBCC and the BCI, according to the aims of the study. Questions were developed that might encourage the women to express their feelings in an uninhibited way and to facilitate the flow of discussion. (Appendix 1)

All participants completed a demographic information form. They were not required to put their names on these forms. Forms were collected at the start of each group.
2.6 Data analysis

The audio-tapes from each group were transcribed verbatim. Content analysis of the data was then undertaken by the two authors, De Morgan and White. Transcripts were read line by line and coded to capture the meaning of the data. The coding was then crosschecked between the two authors to confirm that they were both assigning the same meaning to the codes. The codes were sorted and major and minor categories were identified. These category descriptions were used to record women's perceptions of their diagnosis and their information, psychosocial, physical and practical needs.

2.7 Ethical considerations

Ethical considerations will be discussed under four themes: minimisation of psychological harm; informed consent; confidentiality of data; and privacy.

2.7.1 Minimisation of psychological harm

It is acknowledged that, receiving information about the project or participating in the focus group interviews may be anxiety provoking for some women. To minimise the risks of psychological harm, a number of procedures were followed:

- All correspondence contained the contact name and contact details of the principal researcher and indicated that she could be contacted at any time with any questions or concerns relating to the project.
- All correspondence with women contained the term “breast disease” rather than “DCIS”, to prevent any confusion or alarm.
- The patient eligibility criteria excluded the involvement of patients who were very newly diagnosed (ie within the preceding six months).
- The patient criteria excluded patients who were considered by their clinician to be too ill to participate.
- The facilitators were trained by counselling staff at the BCI in dealing with potential issues of concern to participants.
- All women who attended the focus group interviews received a leaflet explaining how to contact the Breast Cancer Support Service if they needed further support or information.
Ethical approval for this study was obtained from the NSW Statewide Health Confidentiality and Ethics Committee (SHCEC).

2.7.2 Informed consent

All women selected for inclusion in the focus group interviews were sent written information about how their names had been obtained, the purpose of the focus group interviews and their proposed role within it. They were informed that participation was entirely voluntary, that they could withdraw at any time, and that a decision not to participate, or to withdraw from the project, would have no influence on any future medical treatment they may receive. A consent form was included with the information letter to provide women with the opportunity to indicate their informed consent to participate in the focus group interviews.

2.7.3 Confidentiality of data

Women were informed that the focus group discussion was strictly confidential and that their treating clinicians would not be informed about any comments they made during discussion. The names and contact details of the women diagnosed with DCIS whom the participating clinicians had identified for the focus group interviews were not given to the research team. The research team only had access to returned reply forms, and only contacted those women who indicated their willingness to participate. Only the principal researcher had access to this information, which was stored separately from the data. All participants were informed that they would not be identified in any report or publications arising from this research. All names and identifying information were removed from excerpts of the transcripts used in publications.

2.7.4 Privacy

Women were informed that this project was undertaken with the approval of the SHCEC body in NSW and that their names had been identified only for the purposes of this specific project, which was expected to be of significant benefit for future DCIS patients. No attempt was made to contact women who indicated that they did not wish to participate in the focus group interviews. No individually identifying data will be cited in any reports arising from the project.
2.8 Limitations of the method

The major limitation of the qualitative investigation is that the results are not generalisable to the wider DCIS population. This is due to the use of a convenience sample rather than a selected sample. Women were recruited to the study by selected clinicians who were known to researchers at the NBCC and the BCI, and had an interest in breast cancer. These clinicians may have been more knowledgeable about the nature of DCIS due to the BCI's involvement in DCIS research and their exposure to the NHMRC Clinical Practice Guidelines for the Management of Early Breast Cancer.

Since the qualitative approach requires a wide variety of people to be involved, optimally women should also have been represented who were not recruited by clinicians affiliated with either the NBCC or the BCI.

This selection procedure was chosen to increase the response rate of surgeons who would be willing to participate in the study and also the response rate of women, who were considered to be much more likely to participate if they were invited by their clinician. However, it must be noted that there would also be a selection bias if women were recruited directly from a database rather than via a clinician. Women who were willing to participate in the study would be likely to be either very satisfied or very dissatisfied with the care they received.
2 Research Method

Experience of diagnosis, information and support needs of women diagnosed with ductal carcinoma in situ (DCIS)
3 Findings from the focus group interviews

3.1 Profile of participants

A total of 26 women participated in the five focus group interviews. Five women participated in the daytime Westmead group, the inner city group, the Liverpool group and the Orange group, and six women participated in the night-time Westmead group.

The women ranged in age from 40 to 73 years, with an average age of 55 years and the most common age range being 60-69 years, as seen in Figure 2.

**Figure 2: Age profile of participants in the focus group interviews**

Nineteen of the women were born in Australia, three in Ireland, two in Scotland, one in New Zealand and one in the Ukraine. Only one woman was from an Aboriginal and Torres Strait Islander background. Twenty-one of the women lived in Sydney and five women lived in Mid Western NSW and the Greater Murray. The women's area of residence by Area Health Service varied according to Figure 3, with the most common areas of residence being Western and Southwestern Sydney.
Twenty-four of the women were married or living in a permanent relationship at the time of the focus group interviews. One woman had separated from her husband and one woman was widowed.

The educational level of the participants varied, as indicated in Figure 4. The most common category was women who had attended universities or colleges (n=8), followed by women who had attended Year 10 or the equivalent only (n=6).
More than one-third of the women were employed at the time of the focus group interviews and more than one-third performed solely home duties, while the rest of the women were either self-employed or retired, as indicated in Figure 5. All women who were retired were excluded from the home duties category.

**Figure 5: Employment status of participants in the focus group interviews**

![Employment status of participants in the focus group interviews](image)

As indicated in Figure 6, the length of time since diagnosis ranged from six months to five years, and the most common length of time was one year.

**Figure 6: Length of time since diagnosis of participants in the focus group interviews**

![Length of time since diagnosis of participants in the focus group interviews](image)
3.1.1 Description of the sample of rural women

Although only five rural women participated in the focus group interviews, a description of their profile is included for comparison with the other women in the study (see Table 1). As the table demonstrates, their educational level, age range, length of time since diagnosis and marital status show a similar distribution to those of the rest of the participants in the study. However, all rural women who participated were either retired or doing home duties. Women who were employed outside home were not represented. There were also no Aboriginal/Torres Straight women or women from non-English speaking backgrounds in the rural focus group.

Table 1: Demographic characteristics of the rural sample of participants in the focus group interviews (n=5)

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<td></td>
<td>60-69 years</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>70-79 years</td>
<td>1</td>
</tr>
<tr>
<td>Language spoken at home</td>
<td>English</td>
<td>5</td>
</tr>
<tr>
<td>Education</td>
<td>Year 10/SC</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>HSC/Leaving</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Technical college</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>University/college</td>
<td>1</td>
</tr>
</tbody>
</table>
3.1.2 How representative were the women in the focus group interviews, including rural women?

The only Australian data available which provides information about the characteristics of the wider DCIS population is from The Annual Statistical Report of BreastScreen Victoria, 1996. Of the 864 cases of breast cancer diagnosed in 1996, 143 (17%) were reported to have DCIS. However, the only demographic data reported was the age profile of the DCIS population in 1996, as demonstrated in Table 1.

### Table 1: Age profile of DCIS population in 1996 in Victoria

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>40-49 yrs</td>
<td>13</td>
</tr>
<tr>
<td>50-59 yrs</td>
<td>44</td>
</tr>
<tr>
<td>60-69 yrs</td>
<td>61</td>
</tr>
<tr>
<td>70-79 yrs</td>
<td>24</td>
</tr>
<tr>
<td>80+ yrs</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>143</strong></td>
</tr>
</tbody>
</table>

In both the DCIS population reported in Victoria in 1996 and the DCIS focus group population reported in this study the most common age range was 60-69 years. However, women were more highly represented in the younger age range in the DCIS focus group population than in the Victorian data, as demonstrated by Figures 7 and 8.

### Figure 7: Age profile of participants from focus group interviews

![Age profile of participants from focus group interviews](image)
However, qualitative investigation seeks to report the range of responses that people give, rather than calculate the proportion of the population giving any particular response/s. In other words, the qualitative approach requires the sample to include a wide variety of people without too much need for concern about whether each type is represented in correct proportion to the larger population. Since the aim is not to obtain a representative sample in the statistical sense, a selected sample is more appropriate to this approach than a random sample.

This qualitative study included a range of women from all appropriate age groups, as seen in the data comparison graphs above. It also included women from various socio-economic backgrounds and areas of residence. However, the qualitative study only included one woman from a non-English speaking background and one woman from an Aboriginal/Torres Strait Islander background, and therefore cannot be considered to represent the range of opinions of women from these backgrounds.
3.2 The needs of women diagnosed with DCIS

The needs of women diagnosed with DCIS are described in four categories: experience of diagnosis, information needs, support needs and adjusting to diagnosis (see Table 2). Each of these will be described in detail. In participating in this research, the women shared their experiences, providing a wealth of data that is not possible to fully report. Exemplars (shown in italics) from the interviews will be used to illustrate the findings. Identifying names and information have been removed to maintain the participants’ anonymity.

Table 2: Categories and sub-categories extracted from focus group interviews with women diagnosed with DCIS

<table>
<thead>
<tr>
<th>Category</th>
<th>Subcategory</th>
</tr>
</thead>
<tbody>
<tr>
<td>Experience of diagnosis</td>
<td>Misconceptions about diagnosis</td>
</tr>
<tr>
<td></td>
<td>Involvement in decision making</td>
</tr>
<tr>
<td></td>
<td>Involvement in clinical trials</td>
</tr>
<tr>
<td>Information needs</td>
<td>Written information</td>
</tr>
<tr>
<td></td>
<td>Verbal information</td>
</tr>
<tr>
<td>Support needs</td>
<td>Psychosocial support</td>
</tr>
<tr>
<td></td>
<td>Support during medical procedures</td>
</tr>
<tr>
<td></td>
<td>Physical support</td>
</tr>
<tr>
<td></td>
<td>Practical support</td>
</tr>
<tr>
<td>Adjusting to the diagnosis</td>
<td></td>
</tr>
</tbody>
</table>

3.3 Experience of diagnosis

The experiences of women in the focus group interviews of being diagnosed with DCIS will be described in relation to three sub-categories: women's misconceptions about diagnosis, women's involvement in decision making and women's involvement in clinical trials.
3.3.1 Misconceptions about diagnosis

The confusion about the nature of DCIS was apparent in all focus group interviews and was raised by the majority of women. As one woman put it:

“Well, have I got cancer or haven’t I? And saying it may turn into dysplastic breast cancer so you haven’t really got cancer but you have.

Only a few women recalled being told they had “DCIS” or “ductal carcinoma in situ”:

The good news is you have got DCIS and not the invasive sort of cancer.

Regardless of whether women recalled being told that they had DCIS or ductal carcinoma in situ, their beliefs about the nature of their disease varied. Beliefs ranged from women thinking that they had an invasive cancer:

Yes, it is malignant. All ten of the biopsies have come back positive.

The breast was riddled with cancer.

to women thinking that they had an early cancer:

It looks like you’ve got the beginning stages of breast cancer.

or a contained, non-invasive cancer:

Yes, it’s definitely cancer. It’s in the milk ducts, which is all just contained.

They never said that I had cancer. It was always that there were cells there that were wrong, so you never had that dreaded cancer word said, it was just a possibility. I never got that feeling, I was never told you have cancer or it could spread, or anything. They told me all the time that it would be contained.

or a pre-cancer:

I’m having a mastectomy for this pre-cancerous condition.

Most women felt upset, shocked or anxious when they were told their diagnosis:

And then I just cried, I couldn’t believe it.
As most women were diagnosed by mammography there was the additional shock of being told that they had a serious disease in spite of the having no symptoms:

*I just couldn’t believe it, because I’ve never ever had a pain or an ache or anything.*

The emotional impact of the diagnosis was affected by women’s perceptions about the nature of their disease. Women who thought they had invasive cancer appeared more distressed by their diagnosis than women who thought they had a pre-cancer or a contained, non-invasive cancer. For many of the women, the word ‘cancer’ was associated with fear of an early, painful death:

*I thought I was going to die on the spot. I didn’t hear anything they said.*

The reactions of women who thought they had an invasive cancer is indicative of the embedded social meaning in the word “cancer” itself:

*But it really wasn’t until I tried to say the word “cancer”, I could tell them everything that was happening to me, but really every time I said “cancer” I burst out crying.*

*Cancer, but it’s just that word! I just couldn’t come to grips with it at all.*

Most women who thought they had a non-invasive or pre-cancer rather than an invasive cancer were relieved by this information:

*No, it sounded almost like a relief ‘cause it didn’t sound as bad as a massive invasive tumour. It sounded containable.*

Women’s understanding of their prognosis also varied. Beliefs ranged from women thinking that their disease could not spread to other parts of the breast or body:

*He said ’Its not cancer in the sound in the word of cancer’, he said ’It does not travel and it does not return’.*

*I was never told, ’You have cancer’ or ’It could spread’, or anything.*

to women believing that their disease could spread to other parts of the body but it had a high chance of being cured with treatment:

*It’s cancer, but its 95% curable.*
to women believing that their disease was an invasive cancer that had the potential to metastasise:

So I was just wondering if there should be an automatic investigation of women's bodies after they have had the treatment and they have been cleared, then just as a formality, have the bone scan and blood test or whatever it is to say you're clear. Should that be a regular thing for someone?

The confusion surrounding a diagnosis of DCIS was influenced by a number of issues that were highlighted in the focus group interviews. Firstly, the use of medical language such as the terms ‘DCIS’, ‘ductal carcinoma in situ’ and ‘carcinoma’. Women were confused by the terms ‘DCIS’ and ‘ductal carcinoma in situ’ and thought ‘carcinoma’ meant invasive cancer:

They don't say cancer, do they? They say MISC or whatever it is. I don't even know what I had! They give it this initial and you think oh well that's alright, you know. But when they say the 'c' word you think, oooh.

Secondly, the confusion surrounding DCIS was compounded by the lack of information available on the natural history of the disease and the relative risks of treatment options in regards to recurrence and developing invasive breast cancer:

Because I think I'm at the cutting edge of research so not a lot of other information is available to give you to say, well if you make this decision then this is likely to be here, because we're creating that history, you know?

Thirdly, the confusion surrounding the diagnosis of DCIS was compounded by the offer of mastectomy for treatment. Since mastectomy is a treatment used for breast cancer, this was considered by many of the women to indicate that their disease was an invasive condition:

They are talking mastectomy and yet somebody else on the other hand is telling me this is a pre-cancerous condition and you really found it hard to gel those together, it didn't seem logical.

I am 38 years old, I am having a mastectomy for this pre-cancerous condition. Am I really overreacting here or what's going on?
The confusion felt by some women about why they needed a mastectomy, was further influenced by the promotion of breast conservation treatment for early breast cancer in the media:

\[\text{Well that's why I don't understand why some women have been having it off and some just having a lumpectomy and when you see the advertisement and read about it in the paper there is no need to promote people to have it off now, they can do a lumpectomy and preserve the breast.}\]

Lastly, women's misconceptions about DCIS may have been compounded by the different explanations given by various clinicians about the nature of the disease and its prognosis. This may reflect the confusion among even health professionals of the nature of DCIS, as reported in the literature, or may reflect a problem with the method of explanation or in-patient recall of information. 46-48

3.3.2 Involvement in decision making

Given the confusion about the nature of DCIS and the lack of available evidence about the natural history of the disease and the relative risks of treatment options, it is imperative that women diagnosed with DCIS are given adequate information and involved in decisions about their treatment according to their individual preferences. The needs of women who participated in the focus group interviews varied in relation to their desire to be involved in making decisions about their treatment, with some women playing a major role and others leaving the decision largely to their clinician.

The decisions of women who played a major role in treatment decision making were influenced by a number of issues, such as the verbal information about treatment options given by their clinician and/or the written information received about their treatment options:

\[\text{He [my surgeon] went through the options. I think his clarity of explaining things was very helpful, so he helped me through the decision.}\]

stories from other women diagnosed with breast cancer or volunteers from the Breast Cancer Support Service (BCSS):

\[\text{They had a lady that came to the hospital, she's had one [mastectomy] herself and she came to me and she told me my options.}\]
the preferences of the woman’s family:

*My husband made the decision for me. Don’t get a mastectomy. Not just now.*

the woman’s own preferences formed as a result of previous cancer treatment:

*So I had my mind made up that if it was cancer I would have to have it off [to avoid the radiotherapy].*

a perception that having a mastectomy would mean a better prognosis:

*What’s a bit of breast tissue, it’s nothing, get rid of the thing [whole breast] and get on with life, you know I want to see my kids grow up.*

and the misconception that radiotherapy meant chemotherapy, with women associating chemotherapy with images of vomiting, hair loss and general debility:

*Well, where the trouble is, we could take it out, we could do massive doses of chemo and radium and all that type of thing or else we could take the breast off and you’re cured.*

The factors which influence treatment decisions – such as written and verbal information, and the misconceptions about radiotherapy – highlight the need for information that is thorough, comprehensible and tailored to the individual, as discussed in section 3.4 below.

Women’s satisfaction with their level of involvement in making decisions about their treatment varied, regardless of their involvement in the decision. Of the women who played a major role in treatment decision making, some were satisfied with their level of involvement and felt empowered by their involvement:

*But when it boils down to it, it’s your decision, nobody else’s. You can only decide what’s right for you.*

However, a few women were anxious because of the difficulty of the decision:

*I realised then it had come to like an emotional decision. I really had to make the decision that was best for me, there wasn’t going to be any great answer on the Internet anywhere.*
Some women found the decision difficult because of the uncertainty about the natural history of the disease and the relative risks of treatment options:

He [my surgeon] can't tell us a lot about what will be the long term prognosis, it's really hard for him to predict in five years time, or even in a year's time.

On the other hand, a few women who played a major role in treatment decision making were dissatisfied with the lack of involvement by their clinician in treatment decision making:

Yes, [the decision was left] too much up to me. I felt I could have done with a little more direction.

I found they didn't tell me one way or the other. They explained this is our alternatives, this is what we can do, you make the decision. Sometimes I wonder, are some women in a good state of mind to make that decision given the fact that some of them are fairly traumatised, but I guess they do it for their own sake now. For litigation and whatever.

Among women who played a minor role in treatment decision making some were satisfied, especially the rural women, with the amount of involvement they had in treatment decision making:

Although I never knew if it was the right or wrong decision but I really did have such faith in [my surgeon] that he would tell me what was right for me.

The doctor explained, I just chose what she advised really. She was an expert and I wasn't.

while a few women were dissatisfied with their level of involvement:

But see some people are not given the choice.

Most women in the focus group interviews were satisfied with the amount of time they were given to make a decision about treatment regardless of how much time they were given:

He said to me, “Go away and think about it for a week and come back, and let me know”. And I thought, well that is really great because when you get all that information thrown at you, you need time to sit down and think out all the options that you have.
Only one woman commented that she felt distressed by being given too much time to make a decision and only one woman felt hurried to make her decision.

A few women sought second opinions from other surgeons, oncologists and general practitioners due to their lack of information about DCIS and their dissatisfaction with the manner of their clinician:

*I walked straight out of the surgery there and got in the car and rang my GP. I obviously felt the need to go and talk to another medical person. The surgeon hadn’t fulfilled my need and given me the information that I needed.*

Most of the women from lower socioeconomic backgrounds did not seek a second opinion. None of the rural women sought a second opinion, but one rural woman said that she knew that this option was available if she wanted it.

Regardless of how involved women were in treatment decision making, most women said they did not regret their decision about treatment. One woman said that she would have preferred to have had a mastectomy to avoid having radiotherapy. Another woman who felt that she was not allowed enough involvement in the decision making process expressed her dissatisfaction with the decision:

*If I could go back and I had a choice, I would do what they did. I would save my breast for sure.*

### 3.3.3 Involvement in clinical trials

Most women from the focus group interviews were not invited to participate in a clinical trial. There are currently no clinical trials available specifically for women diagnosed with DCIS. Of the women who were asked to participate in a clinical trial a number of issues were highlighted that were consistent with the literature. First, there was a concern by one woman who was asked to participate in a clinical trial that by not participating would adversely affect her medical care. Another woman who participated in the focus group interviews felt that support from her clinician did diminish after she refused to participate in a clinical trial about tamoxifen. Secondly, there was a desire for choice, which would be prohibited by involvement in a clinical trial. Thirdly, there was a need for women to be better informed about the treatment modalities involved in the clinical trial. For example, one woman who participated in the focus group interviews was involved in a
three-year tamoxifen trial and had believed that tamoxifen would prevent all types of cancers from occurring:

I'd actually been taking tamoxifen for three years but last year I ended up with bowel cancer. I thought tamoxifen would stop me ever getting anything else.

### 3.4 Information needs

The information needs of women in the focus group interviews will be described in relation to two sub-categories: written information and verbal information.

#### 3.4.1 Written information

Women identified the availability of adequate written information about DCIS as crucial. This is particularly important in helping to alleviate the confusion about the nature of DCIS and to assist in treatment decision making.

Most women had not heard about DCIS before their diagnosis despite, high levels of awareness of breast cancer from previously diagnosed women and the media. Women stressed the importance of being well informed in order to be able to make the best treatment decision:

*With DCIS you have to decide whether you want to have a mastectomy or whether you want to have radiotherapy or whether you want to have a lumpectomy or whatever and it’s really up to you, and so therefore that indicates that you need a lot of information and you need a lot of help to make that decision.*

Women felt that written information was essential in helping them formulate questions to ask their clinicians so that they could more fully understand the nature of DCIS and the available treatment options:

*I think it’s critical for [the] early diagnosed to get accurate, up-to-date information, whether it’s pamphlets or whatever that are continuously kept up-to-date in GP’s places or screening clinics – I’ve met women who say it. I didn’t think of any questions until after the operation, or whatever. No one sat with me and explained a pamphlet or helped me formulate my questions. ‘ A lot of women can’t put words to their experience.*
Availability of written information was also considered to be important for family members, especially as the woman herself may be in shock from the diagnosis and unable to fully comprehend the material:

_They gave me heaps of information, but none of it sank in. My husband read the whole lot._

Women’s satisfaction with written information was influenced by a number of factors, such as their individual preferences, the amount of information they received, the style and reading age level of the written material, and the delivery mode of the material.

Despite most women being satisfied with the amount of written information they received about early breast cancer, most women expressed dissatisfaction with the amount of information they received specific to DCIS:

_They gave you plenty of stuff on breast cancer and radiotherapy and all those sorts of things, but on the specifics of actual DCIS there wasn’t a lot._

Only one woman received information specific to DCIS, which involved a photocopied page from a medical text about DCIS.

Women expressed dissatisfaction with the amount of information available about the prognosis of DCIS. The lack of information about the relative risk of various treatment options made the treatment decision even more difficult for some women:

_Because he can’t tell us a lot about what will be the long-term prognosis it’s really hard for him also to predict in five years time, or even a year’s time._

The lack of information about the nature of DCIS and its prognosis affected a few women’s faith in their clinician, a factor that many of the women in the focus group interviews felt was important in maintaining a positive outlook after their diagnosis:

_But you still feel at the end of the day it’s inconclusive. Well, I feel like I’m on some kind of see-saw of medical incompetence._
Even two of the women who were nurses, with greater accessibility to information, were dissatisfied with the lack of specific information about DCIS.

The lack of information about DCIS led women to seek specific information from various sources, including Medline database, the Internet, bookshops and libraries:

> I went to the feminist bookshop, I went anywhere I could think of that had stuff on women’s health and particularly things on DCIS. To find DCIS like I went through endless books.

Women’s satisfaction with written information received about breast cancer – such as booklets and pamphlets – also needs to be considered. Apart from the amount of information women received, the style and reading age level of this written material also influenced their satisfaction with the information. Some women felt that the written information they received about breast cancer was too detailed, and at times difficult to understand:

> I don’t know. I think the more you read sometimes less is more and particularly when you are not qualified you know you are not a physician, so therefore I think sometimes the more you know is often worse, so I think if you know the basics.

> There was more in it than we needed.

This resulted in a few women reporting that they felt anxious or depressed:

> It’s oversaturation and you become paranoid about it.

> I can’t read this, it’s too depressing.

Women’s satisfaction with written information about breast cancer was also influenced by the delivery mode of the material. Women were more satisfied when the information was offered to them rather than when they had to seek information out themselves. Despite this most women felt that women diagnosed with DCIS should not be passive recipients of information, rather that they should actively seek the information that they need:

> I think sometimes it’s a two-way street too, that you have to find out the information also. If your heart’s in it you have to make that effort.
Overall, women expressed the need for information addressing the nature of DCIS, the treatment options available, and the current research about the natural history and relative risk of treatment options. Some women also expressed interest in receiving information about the perceived possible risk factors for DCIS, such as the use of Hormonal Replacement Therapy (HRT) or a high-fat diet. Most women in the focus group interviews also felt very strongly about the need for information in the community about the early detection of DCIS and breast cancer.

_The one thing I feel very strongly about is that women need to be more educated about early detection. I think early detection saved my life through a routine mammogram. Don’t be scared, go and have [one] – you could save your life! Are we saying that loud enough? And clear enough to women? Are we actually getting through with the message? You can save your life if you have a mammogram._

### 3.4.2. Verbal information

Verbal information, given largely by surgeons, was considered to be the most important information source, to which written information was merely supplemented:

_“I don’t really think a pamphlet’s the answer. I think somebody sitting down and talking to you one-to-one.”_

Thorough and clear verbal information was considered to be crucial in conveying the nature of DCIS and the treatment options available, especially considering the confusion and complexity of information in this area. Women who were satisfied with the verbal information they received often desired less written information than women who were dissatisfied with the verbal information they received:

_“I had a very good surgeon who explained things to me. I couldn’t have had it better for information and that.”_

Women’s satisfaction with the verbal information they received was influenced by a number of factors such as women’s individual preferences, the amount of verbal information they received:

_“There hasn’t ever been a question that he’s not prepared to go and find an answer to.”_
and the ability of women to comprehend the information:

But I didn’t feel he went over my head like they do.

The need for comprehensible verbal information was highlighted by the desire for an interpreter by a woman from a non-English speaking background:

I thought it must be a mistake, maybe check again. So I went there with my interpreter and she translated everything and I understood everything.

The style of presentation also influenced women’s satisfaction with the verbal information they received. Women commented on the usefulness of diagrams drawn by clinicians and the use of percentages when discussing prognosis:

I think the way they explained it I didn’t need to think about it because they really went into every detail with the pictures and the percentages.

One woman felt that an analogy used by her surgeon was very helpful in explaining the disease:

I think often with the calcification they’re saying it’s just when you’re old and you get rust in your pipes and you know, and you can get this mental picture, but at the same time it’s a good way to explain it. And then you’re passing on that message to someone else and then they can laugh at it too.

Furthermore, women who were satisfied with the verbal information they received were also more satisfied with the psychosocial support they received than those women who were dissatisfied with the verbal information:

He is a fantastic surgeon and a fantastic person. He’ll sit down with you and discuss it. He even draws you diagrams.

3.5 Support needs

The support needs of women in the focus group interviews will be described in relation to four sub-categories: psychosocial support; support during medical procedures; physical support; and practical support.
3.5.1 Psychosocial support

Psychosocial support was considered by women who participated in the focus group interviews to be a very important component of care. Most women who participated in the focus group interviews were satisfied with the psychosocial support they received. Women who were satisfied with their psychosocial support reported being less anxious and depressed and had a more positive outlook about their prognosis, and this is consistent with the literature. Sources of psychosocial support included the woman’s surgeon and radiation oncologist, the BCSS or a counsellor at the hospital, other members of their treatment team including their general practitioner, other women who had been diagnosed with breast cancer or DCIS, family members, close friends and colleagues.

Most women were satisfied with the support provided by their clinicians. Satisfaction with the level of support provided by their clinician was influenced by a number of factors, including the manner of the clinician:

- He has respect for your feelings and your individual needs and where you were at, and yeah – he’d do anything that he could to help.

- She sits and talks to you as if you’re her dearly beloved.

- I’ve not gone back. I’ll tell you why, really because of his manner. He doesn’t treat the person, he treats the breast.

how the woman was told her diagnosis:

- The surgeon I had he actually told me on his own. I was in hospital when he told me with no one else around. Which I thought was one of the most marvellous things. It was a really good way to be told, because a lot of times you’re told with four or five around and you feel you can’t really show a reaction.

- I was actually told I had cancer at work, over the phone by my surgeon!

the support given to family members by the clinician:

- I like the way he treated me and my husband. He wasn’t just talking about my breast or research or being very clinical. He took time to get to know me and the family and he never stood over me.
the provision of adequate verbal and written information by the clinician, and the clinician’s willingness to answer their questions:

*There hasn’t ever been a question that he’s not prepared to go and find an answer to.*

The general practitioner was also described by women as an important source of support. While most women were satisfied with the level of support and involvement by their general practitioner, a few women felt abandoned by their general practitioner after diagnosis:

*My GP really didn’t involve herself from that point onwards [after I saw the surgeon]. So I had no other backup support, I couldn’t go and talk to her about it or anything like that.*

Women were largely satisfied with the psychosocial support provided by the BCSS. Most women were either contacted by the BCSS or were given pamphlets or personally informed about how they could contact the BCSS if they needed more support. Most women’s experiences of the support given by the BCSS were positive, and they stressed the importance of this support in their overall wellbeing:

*It would have been an hour and I just sat and it just all came out and it was great, because she sat there and she listened.*

*So reassuring and for her it was six years ahead of me, to know about her recovery and all that sort of stuff I found helpful.*

Women were particularly satisfied with the support they received when they were contacted by the BCSS and did not have to initiate contact themselves. Some women felt reassured just knowing they could contact the BCSS if they needed:

*I think you are aware of the fact that you can call your doctors and you can call the Breast Clinic cause you know they are there if you want them, so it’s a backup.*

Problems associated with the BCSS reported by women in the focus group interviews included the inappropriate matching of volunteers, with most women not being matched with other women with DCIS and a few women being matched with women with advanced breast cancer:

*I saw a counsellor here and she told me her story, which was of no help to me at all because it was so different and I thought, “I haven’t come really to hear your story”. Because what she had was a completely different cancer to me.*
3 Findings from the focus group interviews

38 Experience of diagnosis, information and support needs of women diagnosed with ductal carcinoma in situ (DCIS)

lack of follow-up contact:

Yes, I was told that I could speak to the counsellor and she would be in contact with me before the surgery and again after. Well, once she got the first appointment at the doctor I never heard from her again.

lack of support for women from non-English speaking backgrounds:

I think the Breast Cancer Council need to have some support group for women of non-English speaking backgrounds.

lack of support during holiday periods, with one woman trying to contact the Breast Cancer Support Service in January but finding no-one available, and lack of support over the weekend:

I need to go back to them tell them [BreastScreen] it's not very helpful to give me this information [my diagnosis] at ten to five on Friday.

Support groups were also considered to be a valuable source of psychosocial support for some women. However, problems areas experienced included some women being refused participation in support groups with women with breast cancer because of their diagnosis:

Well I rang [the hospital] to see if I could join a support group and I was told I wasn't suitable because what I had was pre-cancer.

and the lack of availability of support groups in some rural areas:

There isn't a counsellor [or] support group of any description. The nearest one I think is Wollongong, there may be one in Goulburn.

Women also stressed the importance of support from family and friends. Some women felt that this was just as important, if not more important than support from the medical team:

I think you know if you do have family support it does make a big difference.

I got most of my support from my doctor and my husband. My husband was just tremendous, he really was.
A few women felt that they received a lot of support from their workplace colleagues. Others commented on the value of talking to women who they had met during treatment, for example at radiotherapy, who were in a similar situation to themselves.

One woman who was privately insured felt very dissatisfied with the lack of continuity of care in the private hospital system (her general practitioner was unsure which surgeon to refer her to):

> I feel let down by the health care system because if I hadn't had private health insurance and I hadn't been sent out there into that treatment maze, if I'd locked into a public health system where I would have had all these facilities laid on for me I wouldn't have gone through what I did.

### 3.5.2 Support during medical procedures

Women who participated in the focus group interviews identified a need for support and information before, during and after medical procedures such as biopsy, ultrasound, and wire localisation. This is particularly important, as many women with DCIS may need to have more than one surgical procedure to establish clear surgical margins. Most women who participated in the focus group interviews were satisfied with the support they received in relation to medical procedures. Women’s satisfaction with the support received in relation to medical procedures was influenced by a number of factors, including how well informed women were before the procedure:

> Well I hadn't been prepared for that, I thought I was coming in for surgery not all this pre stuff [that] needed to happen. Well I was told I was going to have this wire [localisation] you know, not the pain and the discomfort that it will cause.

> I didn’t know what it would be like for a breast and I found that really trying that hour and a half, and didn’t know about the little tattoos and things until it happened and having your photograph taken when you’re all dishevelled.

during the procedure:

> I couldn’t praise them [radiotherapy technicians] enough with how they explained every step of the way and about the tattoo.
and after the procedure:

I went home and I had [this] huge bandage on. I had no idea. I was scared. I didn't know what I was going to see when I took that bandage off. I didn't know if I had half a breast, quarter of a breast and eighth of a breast, a piece of a breast, I had no idea. They said nothing.

the manner of the technician:

A doctor and the fellow who did the ultrasound and they sort of grunted, that's how they communicated, one on one side of the bed and the other peering at the screen.

The nurse who was doing the biopsy was in a panic, had no time to speak to me. There was a lady in the back room screaming her head off. The anaesthetist when I eventually got into the theatre said to me: “Oh, so you like the torture chamber”.

One technician said to me “Oh, you've got lovely skin”, and the other one said: “Well, she won't have by the time this is finished”.

and the psychosocial support available while waiting for test results:

Just that waiting, waiting, waiting, waiting it was like longer than you'd ever experienced.

Am I going to live [or] am I going to die?

3.5.3 Physical support

Most women were satisfied with the physical support they received after surgery. Women's satisfaction with the physical support provided was influenced by whether or not they were referred to a physiotherapist shortly after surgery:

I had some general stiffness in my arm and I complained to people that I saw about it and they said, “Oh it'll get better”, and it is only just now that I've gone to physio to get help with it. And I think that's a bit of a shame really. He said, “You should have come four weeks after the operation and it wouldn't have been so stiff”.

and the availability of follow-up care after leaving hospital. This was particularly important for rural women:

I rang the hospital here and they said, “Oh no, go up the hospital [my nearest hospital to get the tubes taken out of my breast], they'd never heard of me, so then we had to chase around and find a doctor and tell him. I found that traumatic.
3.5.4 Practical support

Most women who needed to wear a prosthesis were satisfied with the amount of information and support they received about prostheses. Most women felt that being fitted for a prosthesis was a positive experience because of the support they received by the assistant:

*They had a lady that came to the hospital, she was lovely, apparently she goes out and talks to ladies that have had a mastectomy, she’s had one herself and she came to me and she told me about it.*

However, one woman was not advised that she could get a prosthesis and six months later was still wearing cotton wool in her brassiere.

None of the rural women were dissatisfied with the lack of information about travel rebates and accommodation while having radiotherapy. Only one rural woman travelled to Sydney for radiotherapy and was able to stay with a member of her family, although she was informed of the availability of alternative accommodation. None of the rural women who chose to have a mastectomy, indicated that their choice was influenced by their reluctance to leave home and travel to a city centre, as has been highlighted in the literature.

3.6 Adjusting to the diagnosis

The literature about breast cancer demonstrates the difficulties women experience in adjusting to their diagnosis. Some of the difficulties that women in the focus group interviews experienced were: coping with the shock of the diagnosis; the physical effects of treatment, particularly the effect on their body image and sexuality; the thought of possible death; the impact of their diagnosis and treatment on their family; and the negative reactions by others about their diagnosis:

*I found that people are actually scared of you. Women are really scared of other women with cancer.*

Women used various strategies to cope with their diagnosis, such as reliance on friendship and religious comfort:

*You couldn’t go through it without friends, and prayer.*
maintaining a sense of hope:

I am a great believer in this: a good attitude and positive thinking – a great believer that it helps healing and all sorts of things in living.

the use of humour:

Try to keep your sense of humour. I know it can be hard at times.

determination not to give up:

Well it didn’t get me 15 years ago and it’s not going to get me now.

and a sense of hardiness about getting on with their life after diagnosis, particularly displayed by the rural women:

Keep a cheerful outlook. Think of what you’ve got left. Yeah well I’m here, I’m alive, the alternative’s not too hot. You know you’ve got a new chance at life.

Right, it’s happened, it’s gone, I’m here and now life goes on.

Women expressed the need to accept the treatment decision made at the time:

You did your best at the time.

Women stressed the benefits of having faith in the medical team:

You need to trust your GP and your surgeon, you need to have great confidence in them.

Some woman discussed the positive aspects of being diagnosed with DCIS, such as the precipitating of the resolution of family issues:

I sought counselling in relationship to my relationship with my mum and how come breast cancer falls in the nurturing part of your body and the social type stuff so in a sense it was a trigger to having to deal with family stuff.

and the diagnosis allowing them to discover their inner strength:

I feel this has brought out an inner strength in me that I never knew I had.

I’m normally really shy and quiet and now I’m changing. It’s really been a good growing thing inside, I don’t know how you explain it.
Most women enjoyed the discussion especially those women who had never talked to other women about their experiences of being diagnosed with DCIS.

### 3.7 Summary of findings

The findings from the focus group interviews conducted with women diagnosed with DCIS highlight a number of important issues. Further research is needed to establish the generalisability of the results to the larger DCIS population. From the findings of this study a questionnaire can be developed to undertake a larger study.

Some of the major issues highlighted by the focus group interviews are outlined in Table 3.

<table>
<thead>
<tr>
<th>Category</th>
<th>Sub-categories</th>
<th>Summary of findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>3.3 Experience of diagnosis</td>
<td>3.3.1 Misconceptions about diagnosis</td>
<td>3.3.1.1 Some women were confused about the nature of DCIS: beliefs ranged from an invasive cancer to an early cancer to a contained, non-invasive cancer to a pre-cancer.</td>
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<tr>
<td></td>
<td></td>
<td>3.3.1.2 Women who thought they had an invasive cancer appeared more distressed by their diagnosis than women who thought they had a pre-cancer or a contained, non-invasive cancer.</td>
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<td></td>
<td></td>
<td>3.3.1.3 Confusion surrounding the diagnosis of DCIS was influenced by the use of medical language. Women were confused by the medical terms ‘DCIS’ and ‘ductal carcinoma in situ’, and thought ‘carcinoma’ meant invasive cancer.</td>
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<td></td>
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<td>3.3.1.4 Confusion surrounding the diagnosis of DCIS may have been influenced by different explanations given by various surgeons and radiation oncologists about the nature of the disease and its prognosis, the method of explanation or patient recall of information in this complex area.</td>
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<td></td>
<td></td>
<td>3.3.1.5 Some women were confused about the prognosis of their disease: beliefs ranged from the disease not spreading to other parts of the breast to having the potential to metastasise.</td>
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<td></td>
<td></td>
<td>3.3.1.6 Some women were confused about why they needed a mastectomy for a ‘pre-cancerous’ condition. This was compounded by media promotion of breast conservation treatment for early breast cancer.</td>
</tr>
<tr>
<td>3.3.2 Involvement in decision making</td>
<td>3.3.2.1 Women's preferences for involvement in treatment decision making varied from women desiring to play a major role in decision making to women desiring to leave the decision largely to their surgeon.</td>
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<tr>
<td>3.3.2.2 The decisions of women who played a major role in decision making were influenced by the verbal information given by their surgeon about their treatment options; the written information they received about their treatment options; stories from other women diagnosed with breast cancer or BCSS volunteers; the preferences of the woman's family; any past history a woman had of cancer treatment; a perception that having a mastectomy would mean a better prognosis; and by the misconception that radiotherapy meant chemotherapy, with the women associating chemotherapy with images of vomiting, hair loss and general debility.</td>
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<tr>
<td>3.3.2.3 Women's satisfaction with their level of involvement in treatment decision making varied, regardless of their involvement in treatment decision making.</td>
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<td>3.3.2.4 Most women were satisfied with the amount of time they were given to make a decision about treatment, regardless of how much time they were given.</td>
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<td>3.3.2.5 A few women sought second opinions, due to the lack of information about their breast disease and/or dissatisfaction with the manner of their clinician.</td>
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<tr>
<td>3.3.2.6 Regardless of how involved women were in treatment decision making, most women did not regret the decision about treatment.</td>
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<tr>
<td>3.3.3 Involvement in clinical trials</td>
<td>3.3.3.1 Issues highlighted included: fear that not participating in a clinical trial would adversely affect their medical care; desire for choice; the need for participants to be well informed about treatment modalities involved in the clinical trial.</td>
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<tr>
<td>3.4 Information needs</td>
<td>3.4.1 Written information</td>
<td>3.4.1.1 Many women were dissatisfied with the lack of written information available specifically about DCIS and its prognosis.</td>
</tr>
<tr>
<td>3.4.1.2 Some women were also interested in obtaining information about the perceived possible risk factors for DCIS, such as Hormonal Replacement Therapy and a high-fat diet.</td>
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<td>3.4.1.3 Women's information needs varied.</td>
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<tr>
<td>Section</td>
<td>Topic</td>
<td>Details</td>
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<tr>
<td>3.4.1.4</td>
<td>Women's satisfaction with written information about breast cancer was influenced by the amount of information they received; the style and reading age of the material; and the delivery mode of the material.</td>
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<tr>
<td>3.4.1.5</td>
<td>Lack of specific information about DCIS affected a few women's faith in the medical profession.</td>
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<tr>
<td>3.4.1.6</td>
<td>Some women sought additional information from Medline database, the Internet, bookshops and libraries.</td>
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<tr>
<td>3.4.2.1</td>
<td>Verbal information was considered to be the most important source of information.</td>
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<td>3.4.2.2</td>
<td>Women who were satisfied with the verbal information they received desired less written information than women who were dissatisfied with the verbal information they received.</td>
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<tr>
<td>3.4.2.3</td>
<td>Women's satisfaction with the verbal information they received was influenced by women's individual preferences; the amount of verbal information they received; the comprehensibility of the information; and the style of information, such as diagrams drawn by surgeons.</td>
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<tr>
<td>3.4.2.4</td>
<td>Women who were satisfied with the verbal information they received were also more satisfied with the psychosocial support they received than women who were dissatisfied with the verbal information.</td>
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<tr>
<td>3.5.1.1</td>
<td>Psychosocial support was considered by most women to be a very important component of care.</td>
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<tr>
<td>3.5.1.2</td>
<td>Most women were satisfied with the level of psychosocial support they received.</td>
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<tr>
<td>3.5.1.3</td>
<td>Sources of psychosocial support included their surgeon and radiation oncologist; the BCSS or a counsellor at the hospital; other members of their treatment team, including their general practitioner; other women who had been diagnosed with breast cancer or DCIS; and family members, close friends and colleagues.</td>
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<tr>
<td>3.5.1.4</td>
<td>Women who were satisfied with the psychosocial support they received were less likely to be report being anxious or depressed.</td>
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</tbody>
</table>
3.5.1.5 Women's satisfaction with the level of support provided by their clinician was influenced by the manner of the clinician; how women were told their diagnosis; the support given to family members by the surgeon; and the provision of adequate written and verbal information by the clinician including the clinician's willingness to answer their questions.

3.5.1.6 Women's satisfaction with the level of support provided by their general practitioner was influenced by whether the general practitioner involved herself/himself in the woman's care after diagnosis.

3.5.1.7 Most women were satisfied with the psychosocial support provided by the BCSS.

3.5.1.8 Problems associated with the BCSS included the inappropriate matching of volunteers; lack of follow-up contact; lack of support for women from non-English speaking backgrounds; and lack of support during holiday periods and over the weekend.

3.5.1.9 Support groups were also considered to be a valuable source of psychosocial support for some women. Problem areas experienced included the refusal of some women being refused the opportunity to participate in support groups with women with breast cancer because of their diagnosis; and the lack of availability of support groups in some rural areas.

3.5.2 Support during medical procedures

3.5.2.1 Some women identified a need for support and information before, during and after medical procedures such as biopsy, ultrasound, and wire localisation; and while waiting for test results.

3.5.3 Physical support

3.5.3.1 Most women were satisfied with the physical support they received after surgery. Women's satisfaction with the physical support provided was influenced by whether they were referred to a physiotherapist shortly after surgery; and the availability of follow-up care after leaving hospital, a particularly important issue for rural women.

3.5.4 Practical support

3.5.4.1 Most women were satisfied with the practical support, they received such as being fitted for a prosthesis and receiving information about travel rebates.
3.6 Adjusting to diagnosis

3.6.1 Difficulties women experienced were: coping with the shock of the diagnosis; the physical effects of treatment, particularly the effect on their body image and sexuality; the thought of possible death; the impact of their diagnosis and treatment on their family; and negative reactions by others about their diagnosis.

3.6.2 Women used various strategies to cope with their diagnosis, such as religious comfort; maintaining a sense of hope; humour; determination about not giving up; and a sense of hardiness about getting on with their life after diagnosis, displayed particularly by the rural women.

3.6.3 Some women discussed the positive aspects of being diagnosed with DCIS, such as the precipitation of the resolution of family issues; and the discovery of their inner strength.
Findings from the focus group interviews

Experience of diagnosis, information and support needs of women diagnosed with ductal carcinoma in situ (DCIS)
4 The needs of women diagnosed with DCIS

4.1 Discussion

The women's stories recorded in this report reveal their experiences of being diagnosed with DCIS. This study demonstrates the confusion surrounding a diagnosis of DCIS. Women's beliefs about the nature of their disease varied, with some women believing that they had an invasive cancer, others an early cancer, others a contained, non-invasive cancer while other women believed that they had a pre-cancer. The emotional impact of the diagnosis was affected by women's perceptions about the nature of their disease. Women who thought they had invasive cancer were more distressed by their diagnosis than women who thought they had a pre-cancer or a contained, non-invasive cancer. Women were also confused about the prognosis of their disease, with beliefs ranging from their disease not being able to spread to other parts of the breast to their disease having the potential to metastasise.

The confusion surrounding a diagnosis of DCIS was influenced by a number of issues that were highlighted in the focus group interviews and need to be addressed. First, confusion arose from the use of medical language such as the terms 'DCIS', 'ductal carcinoma in situ' and 'carcinoma'. Women were confused by the terms 'DCIS' and 'ductal carcinoma in situ' and thought 'carcinoma' meant invasive cancer. The authors agree with pathologists such as Foucar who question the use of the term 'carcinoma' in relation to a non-invasive disease with a diverse malignant potential. This may be confusing risk with disease. The term ‘carcinoma in situ’ was an appropriate term when it was coined in 1932 for high-grade lesions of high malignant potential found in symptomatic women. However, with the current detection of large numbers of lesions by mammography, low-grade lesions of low malignant potential are being detected, thus questioning the appropriateness of the term ‘carcinoma’.
Secondly, the confusion surrounding DCIS was compounded by the lack of information available about the natural history of the disease and the effectiveness of treatment options in regards risk of recurrence and of developing invasive breast cancer. Women in the focus group interviews expressed dissatisfaction with the amount of written and verbal information they received about DCIS, especially in regards to their prognosis. Research has shown that women who are satisfied with the information they receive have increased levels of psychological wellbeing. Research has also demonstrated that women's preferences for information can change throughout the diagnostic and treatment process.

Thirdly, the confusion surrounding the diagnosis of DCIS was compounded by the use of mastectomy as a treatment option for women diagnosed with DCIS. Since mastectomy is a treatment used for breast cancer, this was considered by many of the women to indicate that their disease was an invasive condition. This confusion was further influenced by the promotion of breast conservation treatment for early breast cancer in the media.

Fourthly, women's misconceptions about DCIS may have been compounded by varying explanations given by clinicians about the nature of the disease and its prognosis. This may reflect the confusion even among health professionals about the nature of DCIS or may reflect a problem with the method of explanation or patient recall of information.

This study highlights the confusion surrounding a diagnosis of DCIS, the difficulty in treatment decision-making in uncertain and complex situation, and the need of appropriate information, tailored to the individual, for women diagnosed with DCIS. As general written information is not able to be tailored to the needs of the particular individual, the most appropriate form of information in complex situation may be verbal information communicated by the patient's primary clinician, such as the surgeon or radiation oncologist.

This study also highlights the importance of appropriate psychosocial support for women diagnosed with DCIS. Women in this study who were satisfied with their psychosocial support reported being less anxious and depressed, and had a more positive outlook about their prognosis. Sources of psychosocial support for a woman diagnosed with DCIS included the woman's surgeon, the radiation oncologist, the BCSS or a counsellor at the hospital, other members of her treatment team including her general practitioner; other women diagnosed with
breast cancer or DCIS; family members, close friends and colleagues. Health professionals can provide support to a woman diagnosed with DCIS by reassurance, by listening to her, and by giving her the opportunity to openly discuss her fears and concerns about her diagnosis and its implications. The woman should also be advised of the support services available to her and her family, and encouraged to use them if she feels the need for more support.

This study highlights the need for support services to be made more relevant to women diagnosed with DCIS. The study revealed a number of issues in the support services, such as the inappropriate matching of volunteers in the BCSS; the lack of opportunity for some women diagnosed with DCIS to participate in support groups with women diagnosed with breast cancer; and the lack of availability of support groups in some rural areas. This indicates a need for the BCSS and other support services to be informed about the nature of DCIS, and to develop protocols for how women diagnosed with DCIS should be supported within the service. Women also indicated a need for psychosocial support and information before, during and after medical procedures such as biopsy, ultrasound, and wire localisation; and while waiting for test results.

Considering that this group of women may have had greater access to information and support than the general DCIS population due to the affiliation of their clinician with either the BCI or the NBCC, there may be even greater confusion among the general DCIS population about the nature of DCIS and even greater dissatisfaction about the amount of information specific to DCIS available to women. This needs to be evaluated in future research. Also, there is a need to evaluate whether women diagnosed with DCIS are more confused about the nature of their disease than women diagnosed with early breast cancer.

4.2 Conclusion

In spite of the small sample size, this study highlighted:

- the value of qualitative research in facilitating in-depth exploration of participants’ experiences, and in exploring areas of limited knowledge or great complexity
- the confusion surrounding a diagnosis of DCIS
- women’s dissatisfaction with the written and verbal information they received specifically about DCIS and its prognosis
• women’s satisfaction with the psychosocial support they receive from their primary clinician
• the lack of appropriate support available to women diagnosed with DCIS within the BCSS and in some support groups

4.3 Recommendations

The significant recommendations that have emerged from this study, that need to be evaluated in future research, are as follows.

Experience of diagnosis

• Health professionals should be informed of the confusing nature of the terms ‘DCIS’, ‘ductal carcinoma in situ’ and ‘carcinoma’ for women, and the effect of these terms on women’s interpretation of the nature of the disease and their consequent emotional state.
• Health professionals should be informed about the current research about DCIS through the development and dissemination of clinical practice guidelines for the management of DCIS.
• Health professionals should explore individual women’s preferences for involvement in treatment decision making throughout the diagnostic and treatment process.
• Women should be allowed one to two weeks to make their treatment decision.
• Women should be assisted in seeking a second opinion if they request one.
• Women should be reassured that not participating in a clinical trial will not affect their treatment in any way.
• Women should be well informed about treatment modalities involved in available clinical trials.
Information needs

- Health professionals should explore individual women's preferences for verbal and written information throughout the diagnostic and treatment process.
- Clear written and verbal information specific to DCIS should be made available to women diagnosed with DCIS, about the nature of DCIS, the medical terms used, the treatment options and the current research about the relative risks of treatment options in relation to recurrence or the development of invasive breast cancer.
- The current evidence concerning risk factors for breast cancer and DCIS should be available if women require it.
- Comprehensible and comprehensive consumer resources about DCIS should be developed.
- Written and verbal information should include diagrams.
- Interpreters should be available to women from non-English speaking backgrounds.
- Verbal information should be provided in a form and manner which is appropriate to each individual woman's circumstances, personality, expectations, fears, beliefs, values and cultural background.
- Information should be available for the woman's family if she requests it.

Support needs

- Surgeons should give support to a woman by reassurance, listening, and giving her opportunity to openly discuss her fears and concerns about her diagnosis and its implications.
- Psychosocial support should also be given to a woman's family by her surgeon, other members of the treatment team or support services, if the woman desires it.
- Women should be advised of the support services available to them, and encouraged to use them if they feel the need.
- General practitioners should be involved in supporting women after the initial diagnosis if the woman desires it.
- Appropriate support should be available to women diagnosed with DCIS within the BCSS.
• Support groups should be available to women diagnosed with DCIS in rural as well as urban areas.

• Women should receive psychosocial support and information before, during and after medical procedures such as biopsy, ultrasound, and wire localisation; and while waiting for test results.

• Women should receive adequate physiotherapy soon after surgery.

• Follow-up care should be available to women, particularly rural women, after leaving hospital.

• Women should be advised about practical issues, such as being fitted for a prosthesis and their eligibility for travel assistance.

### Adjusting to the diagnosis

• Women should be given adequate support and information about coping with the shock of the diagnosis; the physical effects of treatment, particularly the effect on their body image and sexuality; the thought of possible death; the impact of their diagnosis and treatment on their family; and the negative reactions from others about their diagnosis.

• Women should be encouraged to maintain hope, a sense of humour and determination about not giving up.

It is recommended that the issues highlighted in this report be used in the development of clinical practice guidelines for the management of DCIS.

These recommendations are in keeping with the guidelines – that is the recently published NHMRC National Breast Cancer Centre Psychosocial clinical practice guidelines: providing information, support and counselling for women with breast cancer (1999). The guidelines state that appropriate detailed information promotes understanding and increases the psychological wellbeing of women with breast cancer; and that allowing women the opportunity to discuss feelings with a member of the treatment team or counsellor decreases psychological distress. Many of the guideline recommendations are based on meta-analyses and randomised controlled trials.
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Experience of diagnosis, information and support needs of women diagnosed with ductal carcinoma in situ (DCIS)
Appendix 1

Focus groups discussion guide – women diagnosed with breast disease

Women’s understanding of their diagnosis

Looking back to the time when you were diagnosed:

- Who first told you that you had breast disease? (eg surgeon, doctor, nurse, other)
- What were the words the person used? (eg What did they call your diagnosis?)
- How did you feel when you were first told about your diagnosis? (eg confused, understood, anxious, scared)
- What did you feel about the way it was explained (eg too abrupt, honest, frank, too matter-of-fact, not clearly explained, not told directly, very supportive, not compassionate, too technical)
- Did anyone else explain your diagnosis to you. Who?
- Did they say similar or different things to the first person?
- Had you heard about this disease prior to diagnosis?
- Do you feel you have a clear understanding about your diagnosis now?
- Scenario: “If you could turn back time what would you like to tell a newly diagnosed person about the disease and how”?
Women’s perceptions of their involvement in decisions about treatment

- How did you decide on your treatment? (eg doctor favoured this one, felt safer that all the disease would be gone, breast size etc)
- Did you get a second opinion?
- Did your family and friends help you decide?
- Did you feel that you had to decide straight away? Or were you given enough time to decide?
- Do you feel that you were involved as much as you wanted to be in making the decision, or too much?
- Did you feel confused about why you needed treatment or the type of treatment you had?
- Would you have preferred a different treatment to the one you had?

Women’s satisfaction with the amount of information they received about different aspects of treatment and support

- How much information have you received about your disease and the different types of treatment?
- Did you receive any pamphlets or books about your disease?
- Would you have like to receive this?
- Did you seek more information than what was given to you? How? (eg Internet, magazines, other doctors)
- Were you satisfied with the amount of information you received?

Women’s perceptions of the psychosocial support they received during diagnosis and treatment

- Who did you receive the most support from? (eg nurse, counselor, GP, surgeon)
- Do you feel that you could discuss your thoughts and feelings as much as you wanted to with the doctors and nurses?
- Did you receive any information about where to get more support or counselling if you or your family needed this? (eg from a counsellor at the hospital or the Breast Cancer Support Service)
Women’s perceptions of the physical support they received during diagnosis and treatment

- Did you feel that you got enough support about any physical problems you had after tests or treatment?

Women’s perceptions of the practical support they received during diagnosis and treatment

- Did you feel you got enough support about practical issues? (eg where to get a prothesis, travel rebates)

Overall

Lastly, before we end the discussion. Looking back at your experience, what would you recommend for women in a similar situation to yourself? What, when & how?

- What advice is critical?
- When should it be given?
- How and by whom?

Other issues

- Are there any other issues you would like to raise that we haven’t discussed already and you feel are important?
- Has everyone enjoyed the discussion today?

In the envelope we gave you there is a number to call if you feel that you would like to discuss further some of the issues that were raised today.
**Time Guide: Suggested allocation per section**

<table>
<thead>
<tr>
<th>Section</th>
<th>Suggested allocation of time (minutes)</th>
</tr>
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<tbody>
<tr>
<td>Formalities and introduction</td>
<td>10</td>
</tr>
<tr>
<td>Women's understanding of their diagnosis</td>
<td>15</td>
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<tr>
<td>Women's satisfaction with the amount of information they received about different aspects of treatment and support</td>
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<tr>
<td>Women's perceptions of their involvement in decisions about treatment</td>
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<tr>
<td>Women's perceptions of the psychosocial support they received during diagnosis and treatment</td>
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<tr>
<td>Women's perceptions of the physical support they received during diagnosis and treatment</td>
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<tr>
<td>Women's perceptions of the practical support they received during diagnosis and treatment</td>
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<tr>
<td>Overall</td>
<td>10</td>
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<tr>
<td>Other issues</td>
<td>15</td>
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<td>Conclusion</td>
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<td><strong>Total Time allocated</strong></td>
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