

The experiences of women diagnosed with ductal carcinoma in situ (DCIS), key communication challenges, and strategies to address them

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two women who died of breast cancer
during the period of my study

my mother
Margaret Josephine Brown

and

my supervisor
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Abstract

The incidence of ductal carcinoma in situ (DCIS) has increased substantially since the advent of widespread breast screening mammography. Unlike invasive breast cancer, DCIS cannot metastasize and a woman cannot die from DCIS unless it develops into invasive breast cancer. However, the natural history of DCIS is not well understood and it is currently not possible to accurately predict which women with DCIS will go on to develop invasive breast cancer. Clinicians are faced with unique communication challenges arising from the fact that DCIS is not an invasive cancer and that the diagnosis, prognosis and treatment of DCIS involve much uncertainty. This thesis sought to understand the experiences of women diagnosed with DCIS by conducting a systematic review of the qualitative and quantitative evidence about the experiences of women with DCIS and a cross-sectional survey of women with DCIS in Australia (N=144). Based on this evidence, recommendations were developed for clinicians about how to effectively communicate with women diagnosed with DCIS. The author examined how and to what extent doctors currently communicate in accord with these recommendations by analysing audio-taped initial diagnostic consultations (N=30) with surgeons (n=13) and women with DCIS at BreastScreen centres in Australia. This study identified factors that are likely to impede women's understanding about their diagnosis and demonstrated the need to develop strategies to improve practice. A DCIS communication aid (CA) was developed and pilot tested to assist clinicians to communicate the diagnosis and treatment of DCIS with women. The CA is currently available in print and online at Cancer Australia. Further evaluation and dissemination of the CA into routine clinical practice, further development and implementation of the recommendations, and incorporation of the CA and recommendations into communication skills training programs has the potential to improve doctor-patient communication about DCIS and increase the well-being and health outcomes of women with DCIS.

Introduction

1 Introduction

Over the past twenty years there has been an expansion of interest in and understanding of the importance of effective communication with patients especially in cancer care.¹

Effective doctor-patient communication is fundamental to patient-centred medicine^{2,3} and has been shown to have many benefits for both patients and clinicians such as improving patient compliance with treatment;^{4,5} increasing patient satisfaction and understanding;^{4,6,7,8} decreasing patient anxiety;^{4,8,9} building a good doctor-patient relationship;^{4,10} decreasing the likelihood of litigation;¹¹ improving job satisfaction and preventing emotional burnout amongst doctors.^{1,12}

Doctor-patient communication has recently been described by de Haes and Bensing as serving the following main functions: fostering the relationship, gathering information, information provision, decision making, enabling disease and treatment-related behaviour, and responding to emotions.¹³ Epstein and Street also identify ‘managing uncertainty’ as one of the key functions of doctor-patient communication.^{2,14} Managing uncertainty involves providing information to patients to both reduce uncertainty and inform patients about irreducible uncertainty.^{15,16} Managing uncertainty also involves helping patients to emotionally cope with uncertainty.^{17,18} For cancer patients, ‘managing uncertainty’ is a key challenge for doctor-patient communication.¹⁵⁻¹⁸

This thesis focuses on the unique communication challenges of ductal carcinoma in situ (DCIS). DCIS is an increasingly common diagnosis in women since the advent of widespread breast screening mammography.¹⁹ DCIS is a particularly challenging communication issue for clinicians for two main reasons. Firstly, DCIS is not an invasive cancer and does not have the capacity to metastasize, that is, spread to other parts of the breast and body and cause death.²⁰ Secondly, the diagnosis, prognosis and treatment of DCIS involve much uncertainty.²¹ The central uncertainty for women diagnosed with DCIS is the inability to know whether their DCIS will progress to invasive breast cancer or the time interval in which invasive breast cancer will occur if left untreated. This uncertainty

complicates treatment decision making for both clinicians and women diagnosed with DCIS.

However, little is known about how doctors should most effectively communicate with women with DCIS to ensure that women understand their diagnosis and its implications and that their needs are addressed. This thesis seeks to understand the experiences of women diagnosed with DCIS, to examine how doctors actually communicate about DCIS to women in clinical consultations, and to develop recommendations and a communication aid to assist doctors to effectively communicate about DCIS and improve women's understanding about their diagnosis. The communication challenges highlighted in this thesis are not only relevant to DCIS but to other non-invasive cancers that are increasingly being detected in this age of screening.

The *Introduction* briefly describes ductal carcinoma in situ (DCIS) of the breast, the uncertainties surrounding the natural history of DCIS, and the current management of DCIS (1.1). This is followed by an outline of the chapters in this thesis (1.2).

1.1 What is ductal carcinoma in situ (DCIS)?

Ductal carcinoma in situ (DCIS) of the breast is defined as the proliferation of abnormal epithelial cells within the milk ducts with all the morphological features of malignancy without invasion outside the basement membrane of the milk-ducts.²² The abnormal cells in DCIS are 'in situ' or 'in place' within the milk ducts compared to invasive breast cancer in which the abnormal cells have spread out of the milk ducts into the surrounding breast tissue. Unlike invasive breast cancer, DCIS does not have the capacity to metastasize, that is, spread to other parts of the breast and body.^{20,23,24} A woman cannot die from DCIS unless it develops into invasive breast cancer.²³

The incidence of DCIS has increased substantially since the advent of widespread breast screening mammography.^{19,25,26} DCIS represents approximately 18% of all newly diagnosed breast cancers (invasive and in-situ) detected by Australia's national breast

screening program (BreastScreen Australia).²⁷ A woman is usually diagnosed with DCIS after stereotactic core biopsy of the breast tissue under local anaesthesia.²⁸ However, stereotactic core biopsy may miss invasive breast cancer in about 15% of women initially diagnosed with DCIS.^{29,30} This means that a proportion of women who were initially diagnosed with DCIS will be diagnosed with invasive breast cancer after surgery.

There is general consensus, derived from the available laboratory and clinical data, that DCIS is a direct precursor to invasive breast cancer.^{23,24,29,31} However, not *all* DCIS will develop into invasive breast cancer.^{21,23,24} The best estimates are that 14%-53% of untreated DCIS may progress to invasive breast cancer over a period of ten years or more.²⁰ No direct observations of the natural history of DCIS are possible due to the current standard of surgical removal of the DCIS.²⁸ Why and how often DCIS progresses to invasive breast cancer, the precise biologic pathway(s) between DCIS and invasive breast cancer, whether any subtypes of DCIS are more likely to progress than others, and how long after the DCIS diagnosis invasive breast cancer would develop is not well understood.^{21,31,32} The uncertainties surrounding the natural history of DCIS complicate treatment decision-making for both doctors and women diagnosed with DCIS.

Prevention of invasive breast cancer is considered the goal of treatment for DCIS.^{21,23,24,31} Treatment options for women with DCIS include breast surgery (breast conserving surgery or mastectomy), radiotherapy (after breast conserving surgery), and hormonal treatments.^{28,29,33} However, controversies exist in regards to the optimal management of DCIS with continuing debate about the use of radiotherapy in all women with DCIS, and the role of hormonal treatments and sentinel node biopsy.^{24,29,34}

Identification of prognostic markers that predict progression to invasive breast cancer is essential for optimal management of DCIS. Prognostic factors such as nuclear grade, tumour size, margin status, and age have been identified as important predictors of local invasive and DCIS recurrence.^{35,36,37} However, identification of better prognostic markers which can determine more precisely which DCIS lesions will progress to invasive breast

cancer is needed to optimise individualised therapy with minimal overtreatment, and undertreatment, of women with DCIS.^{21,23,24,31}

Survival rates following treatment for DCIS are high, with the overall ten-year mortality rate after treatment for DCIS being less than 2%.³⁸ Most women diagnosed and treated for DCIS will not develop invasive breast cancer.^{34,37} The risk of developing invasive breast cancer after treatment for DCIS depends on the woman's prognostic factors and the type of treatment.^{35,37} The *overall* ten-year local invasive recurrence rate is 8% in women treated by breast conserving surgery and radiotherapy³⁴ and less than 1% after a mastectomy.³⁷

1.2 Outline of the chapters in this thesis

While there has been extensive study of the experiences of women with invasive breast cancer,³⁹ there has been much less investigation of the impact of a diagnosis of DCIS and there have been no reviews of existing studies. *Chapter 1* describes a systematic review of the qualitative and quantitative evidence about the experiences of women diagnosed with DCIS. The review outlines the processes involved in the data synthesis and illustrates an approach to synthesising qualitative and quantitative evidence. In addition, the review appraises the quality of the identified relevant studies and highlights areas of need for future research with women diagnosed with DCIS.

Chapter 2 describes a cross-sectional survey of women diagnosed with DCIS in Australia (N=144) within the first year after their diagnosis. This study examines a number of important areas not examined in the studies described in the review in *Chapter 1*. The study aims to assess knowledge, satisfaction with information, treatment decision-making, and psychological morbidity among women with DCIS, and to explore the factors associated with less knowledge and greater confusion about DCIS. The survey includes open questions to provide qualitative data that could add meaning and understanding to the quantitative data,⁴⁰ considered to be particularly important in this study due to the complexity of DCIS.

Chapter 1 and *Chapter 2* provide a greater understanding of the needs of women with DCIS and the areas of confusion and misunderstanding for women with DCIS. Based on the evidence in *Chapter 1* and *Chapter 2*, recommendations were developed for clinicians that outline how to effectively communicate with women diagnosed with DCIS to improve doctor-patient communication and women's understanding about DCIS. To date there are no comprehensive evidence-based recommendations that address the particular needs of women with DCIS. *Chapter 3* describes the first stage of development of recommendations, referred to in this thesis as *Key Communication Elements (DCIS)*. The *Key Communication Elements (DCIS)* address key aspects of the diagnosis, prognosis, treatment and support of women with DCIS.

There is a need to understand how clinicians currently communicate in practice about DCIS and whether there are gaps between what might be ideal and how clinicians actually communicate in real consultations with patients. Understanding how clinicians communicate in practice is vital to guide future interventions to improve communication. *Chapter 4* examines how and to what extent doctors currently communicate in accord with the *Key Communication Elements (DCIS)* developed in *Chapter 3* by analysing audio-taped initial diagnostic consultations (N=30) with surgeons (n=13) and women with DCIS at BreastScreen centres (government funded mammographic screening centres) in Victoria, Australia. No published study to date has examined how doctors communicate about DCIS to women. Given the complexity of DCIS and the need for a deeper understanding of doctor-patient communication about DCIS, the study uses both quantitative and qualitative methods to examine communication in diagnostic consultations.

Communication aids are an emerging technique that have been shown to improve doctor-patient communication and patients' understanding of information.^{41,42,43,44} In *Chapter 5*, a DCIS communication aid (CA) was developed and pilot tested to assist clinicians to communicate the diagnosis and treatment of DCIS with women. There are no published study to date about interventions designed to improve doctor-patient communication and women's understanding about DCIS. The CA is based on the *Key Communication Elements (DCIS)* and is intended to be used by clinicians during their consultations with women with

DCIS. *Chapter 5* examines women's and clinicians' perceptions of the CA in terms of their satisfaction with the content, design and diagrams in the CA; and their perceptions of the benefits of the CA, its impact on doctor-patient communication, and the feasibility of using the CA during clinical consultations.

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Chapter 1

The experiences of women diagnosed with ductal carcinoma in situ (DCIS): a synthesis of qualitative and quantitative evidence in a systematic review

1 Introduction

Ductal carcinoma in situ (DCIS) is an increasingly common diagnosis in women since the advent of widespread breast screening mammography.¹ While DCIS does not have the capacity to metastasize or cause death it can develop into invasive breast cancer over time.² DCIS often requires significant treatments such as breast surgery and radiotherapy to prevent invasive breast cancer from developing in the breast.³

While extensive study of the experiences of women with invasive breast cancer has been critical to driving the development of information for women, guidelines for clinicians and other interventions for improving care,^{4,5,6,7} there has been much less investigation of the impact of a diagnosis of DCIS. There is an emerging literature using both qualitative and quantitative methods that suggests that women with DCIS may have a significant need for better information and support. However, there has been no review that attempts to integrate the findings of existing studies and thus provide the understanding necessary for developing guidelines and interventions to ensure that the needs of women with DCIS are met.

This chapter describes a systematic review of the qualitative and quantitative evidence about the experiences of women diagnosed with DCIS. There is a growing interest in mixed method synthesis, or the integration of qualitative and quantitative evidence in systematic reviews.^{8,9,10} Integrating qualitative and quantitative evidence in this review was considered to be particularly important in order to make optimal use of all forms of evidence from this small area of literature. Furthermore, researchers of mixed method synthesis suggest that qualitative evidence provides additional insights to quantitative evidence and enables a greater understanding of quantitative evidence.^{11,12,13,14}

This chapter has four main aims. First, this chapter aims to integrate the qualitative and quantitative evidence about the experiences of women diagnosed with DCIS. The research question for the review was: *What are the experiences of women diagnosed with ductal carcinoma in situ (DCIS)?* The research question was purposely constructed in broad terms

to prevent restricting the review findings by evaluating particular outcomes, themes or concepts conceived prior to the review.^{8,14}

Second, this chapter aims to illustrate an approach to synthesising qualitative and quantitative evidence in systematic reviews. There is very little guidance and few examples of how to synthesise qualitative and quantitative evidence in systematic reviews.^{11,14,15,16}

The UK Evidence for Policy and Practice Information and Co-ordination Centre (EPPI-Centre) suggests that evidence from diverse study types (quantitative, qualitative and mixed methods research) be synthesised by using thematic analysis for data from non-intervention studies ('view' studies) and where possible meta-analysis of data from trials.^{11,12,17}

However, there is a lack of guidance about the processes involved in using thematic analysis to synthesise qualitative and quantitative evidence from non-intervention studies.

There are some examples of using thematic analysis to synthesise qualitative evidence only^{12,13,18,19} but only a few examples of using thematic analysis to synthesise qualitative and quantitative evidence from non-intervention studies.^{20,21,22} Other possible methods used to synthesise qualitative evidence that may be suitable for synthesising qualitative *and* quantitative evidence from non-intervention studies include narrative summary,¹⁴ meta-ethnography,²³ and meta-summary.¹⁰ However, there are few examples of these methods for synthesising qualitative and quantitative evidence.¹⁰ This chapter illustrates an approach to synthesising qualitative and quantitative evidence in systematic reviews using thematic analysis (*see Methods, Data synthesis, Page 26*).

Third, this chapter aims to appraise the methodological quality of the studies included in the review. There is a growing recognition that reviewers of qualitative and quantitative evidence should consider quality issues.²⁴ It was not the intention of the quality appraisal in this review to rate the quality of the studies using a rating scale or to exclude any studies due to poor quality. Consideration of the methodological quality of the studies was used to assess the credibility of the findings and to identify opportunities to strengthen research in the future.

Fourth, this chapter aims to identify areas of need for future research that could provide vital information to guide interventions to improve communication and ensure the psycho-social and physical wellbeing of women with DCIS.

2 Methods

2.1 Selection criteria

2.1A Types of participants

Studies were included if they involved women diagnosed with ductal carcinoma in situ (DCIS). Studies were excluded if they pooled the data from women with DCIS and women with invasive breast cancer in the reporting of the study findings.

2.1B Types of studies

Only published studies that were available in the English language were considered for the review. Descriptive studies such as observational studies (cross-sectional studies, longitudinal cohort studies and case-control studies) and qualitative studies were eligible for inclusion in the review. Intervention studies such as randomised controlled clinical trials, pseudo-randomised trials or non-randomised trials; or reviews of the descriptive literature, commentaries or opinion-based studies were not eligible for inclusion in the review.

2.2 Search strategy

Electronic literature searches were performed using MEDLINE and PsycINFO databases (1997-2009). As shown in *Table 1.1*, the search strategy included identifying appropriate participants. However, given the broad research question, *What are the experiences of women diagnosed with ductal carcinoma in situ (DCIS)?*, relevant outcomes were not

identified in the search strategy so as not to restrict the number of studies that were eligible for inclusion in the review. Reference lists of identified papers and publication lists of key authors were also manually searched for additional studies.

Table 1.1: Search strategy for the review

MEDLINE and PsycINFO	
1	non\$invasivebreast\$.mp.
2	pre\$invasivebreast\$.mp.
3	ductal carcinoma in situ.mp.
4	intraductal breast\$.mp.
5	DCIS.mp.
6	exp Carcinoma, Intraductal, Noninfiltrating/nu.px [Nursing, Psychology]
7	1 or 2 or 3 or 4 or 5 or 6 (limited to English language and yr: 1997-2009)

2.3 Study quality assessment

The study quality assessment describes the quality of the studies and any methodological concerns of the studies included in the review (*see Results, Study quality and methodological limitations, Page 34*). Table 1.5 in the *Results* (*see Page 39*) also includes information about the attributes and limitations of each study.

Two quality assessment lists were developed for the review to provide guidance for appraising the quality of the studies and are discussed below. There was no intention to rate the quality of the studies using the lists as rating scales.

2.3A *Quality appraisal of the quantitative evidence*

A comprehensive list of criteria for appraising the quality of observational studies was developed by the author from existing quality assessment lists,^{25,26,27,28} the STROBE Guidelines for reporting observational studies,^{29,30} and theoretical papers about how to assess validity and reliability in quantitative studies.^{31,32,33,34,35,36} *Table 1.2 (see Page 22)* outlines the list of criteria for appraising the quality of observational studies.

Issues of consideration in developing the list of criteria for quality assessment of observational studies included: i) adequate reporting of key aspects of the study such as the rationale, study design, sample, recruitment procedures, measurement, and analysis; ii) reliability of the measures, that is, measurement accuracy involving internal consistency and reproducibility;³⁶ iii) internal validity of the measures, that is, the extent to which an instrument measures what it purports to measure;³⁶ and iv) external validity or generalisability, that is, the extent to which the findings can be applied to other groups and populations.³⁰

2.3B *Quality appraisal of the qualitative evidence*

There is much debate about how to appraise the quality of qualitative studies.^{37,38} The use of checklists and criteria for quality assessment of qualitative studies has been criticised due to the difficulties in reconciling differences in study design or theoretical approaches between qualitative traditions and within each tradition.^{8,13,37,39} There is also criticism that criteria are usually based on positivist or post-positivist paradigms^{24,40} which assume that there is one truth independent of human perception as opposed to constructivist or interpretive paradigms which assume there are multiple truths or realities based on our perceptions.^{14,37,38}

Whilst acknowledging the limitations of quality assessment criteria for qualitative studies, a list of criteria was developed by the author for appraising the quality of qualitative studies.

The quality assessment criteria are not representative of a particular qualitative tradition but were developed to be applicable to most qualitative traditions.

The list of criteria for appraising the quality of qualitative studies included in this review was developed from existing quality assessment lists;^{35,41,42,43} and theoretical papers about the nature of qualitative research.^{35,41,43,44,45} *Table 1.3 (see Page 24)* outlines the list of criteria for appraising the quality of qualitative studies. Issues of consideration in developing the list of criteria for quality assessment of the qualitative evidence included: i) adequate description and justification of the theoretical framework and research design; and appropriateness of the research question, sample size, data collection method, type of analysis and conclusions to the particular qualitative tradition; ii) adequate description and justification of techniques such as triangulation, member checking and involvement of multiple researchers in the analysis in terms of either increasing understanding of complex phenomenon (constructivist position) or reaching agreement among different sources (positivist position); iii) reflexivity, that is, an attitude of attending systematically to the context of knowledge construction, especially to the effect of the researcher, at every step of the research process; iv) transferability, that is, the range and limitations for application of the study findings, beyond the context in which the study was done; and v) relevance of the findings to current knowledge, policy, and practice.

Table 1.2: Criteria for appraising the quality of observational studies

Criteria	Observational studies eg longitudinal cohort, cross-sectional and case-control studies
Rationale	<ul style="list-style-type: none"> Was there sufficient theoretical background to justify the study aims? Were the study aims clearly described?
Study design	<ul style="list-style-type: none"> Was the study design appropriate to the study aims and described adequately?
Participants	<ul style="list-style-type: none"> Was the eligibility criteria clearly described, including exclusion criteria eg women previously diagnosed with invasive breast cancer? If relevant, was there a clear definition of the disease or condition? Were characteristics of study participants eg age, education, employment, ethnicity, treatment type(s) reported? Was there a clear definition of any comparison or control group eg women diagnosed with invasive breast cancer? Were characteristics of any comparison or control group reported and compared? Were there any significant differences between groups? If case-control study, were cases and controls adequately matched?
Sample size	<ul style="list-style-type: none"> Did the study explain how the study sample size was arrived at? Was the study sample size, or size of subgroups for analysis, adequate? (A study should be large enough to obtain a point estimate with a sufficiently narrow confidence interval to meaningfully answer a research question.)
Recruitment and follow-up	<ul style="list-style-type: none"> Were the recruitment procedures of study participants, including any comparison or control group, adequately described? eg setting, locations, relevant dates, including periods of recruitment, follow-up (if cohort study), data collection Was the sample representative of the study and target population? Were there any potential selection biases? Examine source of sample eg cancer registry, hospital(s) or breast clinic(s), self-selected, and characteristics of source eg teaching or community based hospitals; and sampling method eg consecutive patients, random sample Were the consent and response rates and reasons for non-participation reported? Were rates high or low? Did the study compare characteristics of respondents and non-respondents? Were there any significant differences between groups? If a cohort study, did the study report the number of participants lost to follow-up and give reasons?

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Criteria	Observational studies eg longitudinal cohort, cross-sectional and case-control studies
Timing of assessment(s)	<ul style="list-style-type: none"> Was the time since diagnosis and/or treatment of the assessment(s), including range, mean and/or median time, reported? Was the initial assessment, if a cohort study, or the only assessment, if cross-sectional or case-control study, a long time since diagnosis or treatment? Was this appropriate to the study aims? Was there a wide range of time since diagnosis or treatment among participants? Was this potential bias reported and addressed in the study?
Measurement	<ul style="list-style-type: none"> Were the outcomes of interest adequately described? Were reliable and valid measures used? Were standardised measures used ie measures had been tested for reliability and validity and published? In what populations were measures standardised? Were measures developed by the researchers tested for reliability and validity and reported? Were measures appropriate or specifically developed for study participants eg women with DCIS?
Analysis	<ul style="list-style-type: none"> Was the analysis, including the variables used, adequately described and justified? Were appropriate statistical tests carried out? Were important features of the tests reported eg means, standard deviations, probability values and confidence intervals? Did the study report and address any potential sources of bias eg differences between respondents and non-respondents groups; differences among participants of the timing of assessment in relation to their diagnosis or treatment? Did the study adjust for any potential confounding factors, eg important demographic and treatment variables? Were they justified by the researchers? Were adequate statistical tests carried out to adjust for confounders eg stratification or multivariate analysis? Were any important potential confounding factors omitted?
Interpretation and generalisability	<ul style="list-style-type: none"> Were the conclusions justified based on the study design and research findings? Were the limitations discussed, taking into account sources of potential bias or imprecision eg small study sample size or small subgroup(s) size? How generalisable is the study ie what populations or subpopulations could the findings be applied to? Examine eg study setting, timing of assessment(s) participant and non-participant characteristics, and outcomes measures assessed.

Table 1.3: Criteria for appraising the quality of qualitative studies

Criteria	Qualitative studies
Rationale	<ul style="list-style-type: none"> Was there sufficient theoretical background to justify the research question(s)? Were the research question(s) adequately described?
Study design	<ul style="list-style-type: none"> Was the particular qualitative research design or theoretical framework described adequately and justified? eg grounded theory, phenomenology, ethnography, biography, narrative, case study Did the authors use triangulation, ie did they combine more than one theory, methodology and analysis in the study? Did the authors justify the use of triangulation eg to increase understanding of complex phenomenon (constructivist position) or to reach agreement among different sources (positivist position)?
Context	<ul style="list-style-type: none"> Was the eligibility criteria clearly described, including exclusion criteria eg women previously diagnosed with invasive breast cancer? If relevant, was there a clear definition of the disease or condition? Was the sampling strategy (eg purposive, theoretical) including setting(s) and location(s) adequately described and justified? Was there any discussion about why people chose not to take part and their characteristics? Were the characteristics of study participants eg age, education, employment, ethnicity, treatment type(s), time since diagnosis reported? Was the sample size appropriate to the particular research design, research questions, data collection and intention of transferability of findings to other settings? Did the researcher(s) critically examine the impact of their role, background and views on the choice of sampling strategy?
Data collection	<ul style="list-style-type: none"> Were the method(s) used for data collection (eg semi-structured or open-ended interviews, focus groups, group interviews, observation, oral histories, documentary sources, diaries) adequately described and appropriate to the particular research design and the study participants? Was data recorded in a transparent and systematic way eg were interviews audio-taped and transcribed? Did the researcher(s) critically examine the impact of their role, background and views on data collection?

continued next page

Criteria	Qualitative studies
Analysis	<ul style="list-style-type: none"> • Was the type of analysis used (eg thematic analysis) and the processes of analysis adequately described and appropriate to the particular research design? How were the various categories identified eg from theory or preconceptions <i>a priori</i>, or developed from the data? • Did the authors involve participants or multiple researchers in the analysis? Did the authors justify the involvement of participants or multiple researchers eg to increase understanding of complex phenomenon (constructivist position) or to reach agreement among different sources (positivist position)? • Was sufficient data presented to support the findings? • Were a range of responses presented; and negative cases or counterhypothesis included and discussed? • Did the researcher(s) critically examine the impact of their role, background and views during the analysis?
Interpretation and transferability	<ul style="list-style-type: none"> • Were the conclusions justified based on the particular research design and findings? • Was a critical evaluation of the transferability of findings to other similar contexts made? • Was the relevance of the findings to current knowledge, policy, and practice or to current research discussed?

2.4 Data synthesis

The purpose of the data synthesis was twofold: i) to summarise or integrate the data and ii) to interpret the data generating new concepts that are not found in the original studies but which help to characterise the data as a whole, a process that is used in primary qualitative analysis.^{8,46}

Thematic analysis was considered the most suitable method for synthesising the qualitative and quantitative evidence in this review given that all of the qualitative studies included in this review used thematic analysis as the method of primary qualitative analysis; and that thematic analysis has been recommended by the UK Evidence for Policy and Practice Information and Co-ordination Centre (EPPI-Centre) as the most appropriate method to synthesise evidence from diverse study types (quantitative, qualitative and mixed methods research) from non-intervention studies ('view' studies).¹¹ Thematic analysis was originally developed for primary qualitative data analysis,⁴⁴ and involves searching for themes that emerge as important to the description of the phenomenon.⁴⁷

As discussed previously, the initial research question for the review was broad: *What are women's experiences of being diagnosed and treated for DCIS?* The review aimed to be guided by emerging findings rather than orientated to the evaluation of particular themes sought within the literature.¹⁴ The structure of the analysis aimed to be inclusive of all the data and did not reflect only findings more frequently reported or more thoroughly explained in the literature. In reporting the findings, counterhypotheses were allowed and the quantitative data were not considered the 'gold standard' if contradictions between the qualitative and quantitative data arose. Thus, the review aimed to integrate the potentially different perspectives of qualitative and quantitative research to enable a greater understanding of women's experiences of being diagnosed and treated for DCIS.

The studies included in the review were coded by hand, largely in order of publication, beginning with the earlier studies. The study 'results' or 'findings', including women's data

(‘quotes’), were coded ‘line-by-line’ into themes and sub-themes. This method is termed ‘axial’ coding in grounded theory.¹²

All data relevant to each coded category were identified and examined using a process called constant comparison in which the data within and between each category are compared for similarities and differences to ensure that the themes and subthemes accurately reflect the material.⁴⁸

The synthesis involved translating the key themes or concepts identified from each study ‘into each other’ to allow for categorisation and comparison.¹² This process of translation is a technique developed specifically for synthesising qualitative evidence in meta-ethnography.²³ There is some debate about the validity of synthesising qualitative research because the process can result in de-contextualizing of studies and their theoretical underpinning.²³ However, translation protects the integrity of the individual accounts, while comparing the key concepts and ideas with those of other accounts.¹⁴ The translation involved a process of constantly checking that the themes and concepts from one study could be validly transferred into another study. The context was also preserved by providing structured summaries of each study, including study aims, setting, sample, methods and study quality appraisal, as highlighted in *Table 1.5* in the *Results* (see *Page 39*).

Identification of themes and subthemes continued until all the studies were accounted for and no new themes and subthemes were discerned. The data were synthesised into 9 themes and 27 subthemes (as described in the *Results*, see *Page 54*) and included ‘descriptive’ themes and subthemes that stayed ‘close’ to the findings in the original studies (for example, *Satisfaction with information*) and ‘analytical’ themes and subthemes involving new interpretive constructs (for example, *Difficulties experienced in treatment decision-making*). Developing ‘descriptive’ and ‘analytical’ themes allowed the synthesis to be both integrative (that is, a summary of the data) and interpretive.^{8,12,14} Themes and subthemes were identified in both the quantitative and qualitative data, in the quantitative data only, and in the qualitative data only, as shown in *Table 1.6* in the *Results* (see *Page 54*).

2.5 Reflexivity

Reflexivity is considered to be an important requirement in primary qualitative studies^{41,43} and therefore was considered an important component in the synthesis of qualitative studies for this review. Reflexivity is an attitude of attending systematically to the context of knowledge construction, especially to the effect of the researcher, at every step of the research process.⁴³

The author's prior research experience and her role in each stage of conducting this review are outlined below.

The research question for this review was developed by the author based on her previous research with women diagnosed with DCIS,⁴⁹ and her involvement with projects at the National Breast and Ovarian Cancer Centre (Sydney, Australia) which provides evidence-based information about breast and ovarian cancer for women, health professionals, cancer organisations, and governments. The research question was broad to prevent restricting the review findings by evaluating particular outcomes, themes or concepts conceived prior to the review.

The literature search strategy, selection criteria, and data extraction method were developed and conducted by the author and discussed with her supervisors to check that systematic procedures were adopted. The lists of quality assessment criteria for observational and qualitative studies were developed by the author based on the current literature and discussed with her supervisors to ensure that the lists were comprehensive and accurately reflected their understanding of the literature. The quality appraisal of the studies was performed by the author and discussed with her supervisors to ensure the results of the quality appraisal were justifiable. Particular attention was given to the results of the quality appraisal of the author's qualitative study⁴⁹ included in the review to confirm that the quality appraisal of this study was valid.

Thematic analysis was chosen by the author to be the most suitable method for synthesising the qualitative and quantitative data in this review, as discussed above. The author had prior experience in using thematic analysis to conduct primary qualitative analysis.⁴⁹ Following the coding of the papers by the author, the data within each code were discussed with her supervisors to increase the author's understanding of the data and to confirm that the codes were justifiable (rather than to reach agreement) as appropriate to a constructivist or interpretive paradigm.

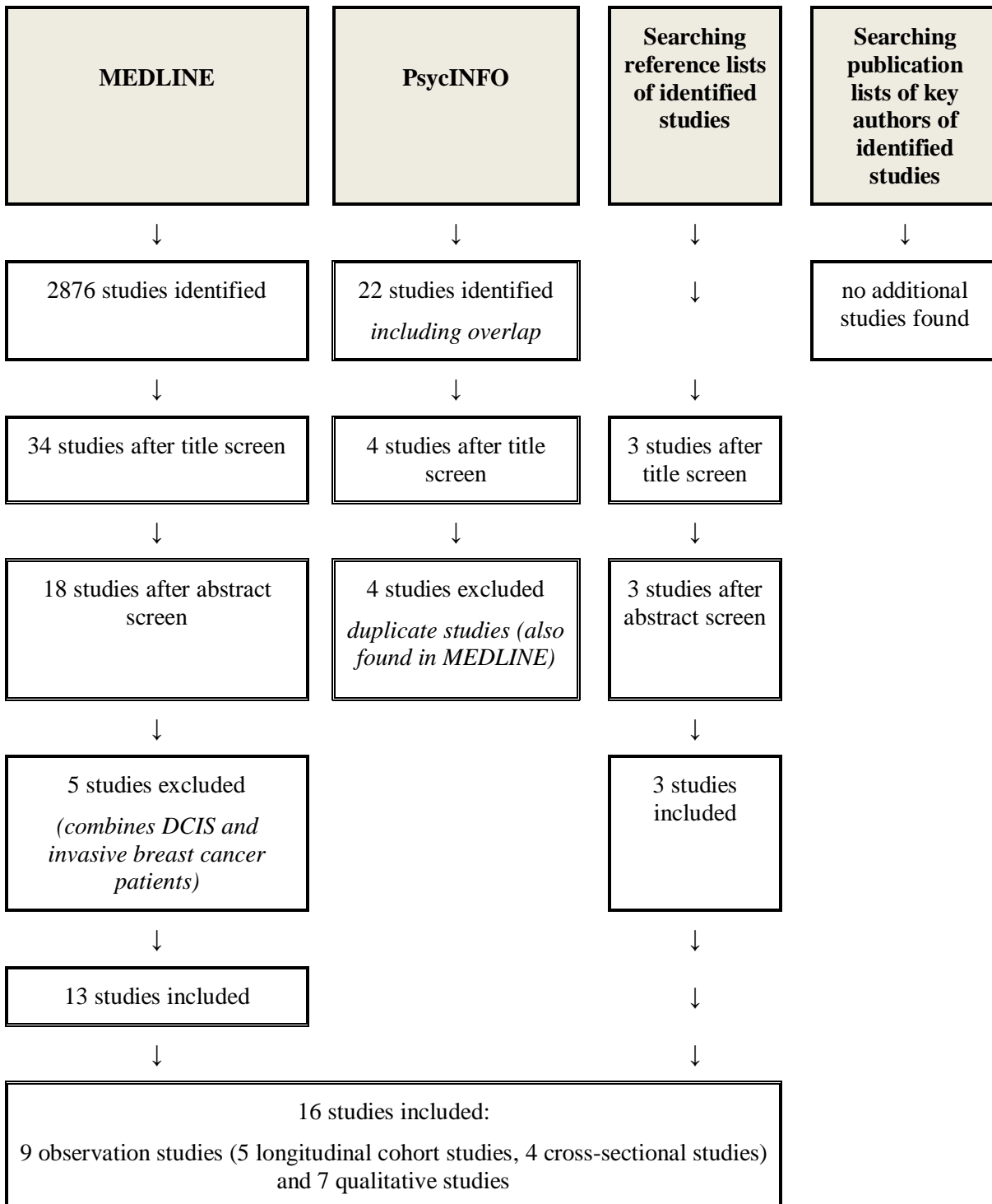
The discussion and conclusions of the review were developed by the author and discussed with her supervisors to ensure the discussion and conclusions were defensible.

3 Results

3.1 Study selection

Figure 1 shows the number of papers included and excluded at each stage of the selection process. The search yielded 2898 studies including duplicates. Studies with titles which indicated they were clearly not relevant to the review were eliminated. The abstracts of possible relevant studies were obtained. These abstracts were reviewed for relevance and compliance with the inclusion criteria. The full papers for all studies which were clearly relevant and complied with inclusion criteria, as well as those for which a decision could not be clearly made, were obtained. These were also reviewed and a final decision was made regarding the included studies. Sixteen studies were finally included in the review.

Figure 1: Study selection



3.2 Study characteristics

Table 1.5 (see Page 39) includes information about the characteristics of each study. It includes the year of publication of the study, first author, study design, measures (for observational studies) and type of analysis (for qualitative studies), sample size and characteristics, country, recruitment source and settings, consent and response rate, and timing of assessment(s).

3.2A Study design

Of the 16 studies included in the literature review, nine were observational studies (including five longitudinal cohort studies^{50,51,52,53,54} and four cross-sectional studies^{55,56,57,58}) and seven were qualitative studies.^{49,59,60,61,62,63,64}

Two longitudinal cohort studies included the same cohort of women,^{50,51} and two other longitudinal cohort studies included another cohort of women.^{53,54} Of the five longitudinal cohort studies, two studies included comparison groups of women with invasive breast cancer,^{53,54} and one study included a comparison group of women without DCIS.⁵² Of the four cross-sectional studies, two studies included a comparison group of women with invasive breast cancer.^{55,56} Most of the observational studies utilised multiple instruments to measure multiple outcomes. In total, 21 different measures were used including seven standardised measures and 14 non-standardised measures as seen in *Table 1.4 (see Page 32)*.

All of the qualitative studies used thematic analysis as the method of data analysis.

3.2B Sample size

Sample sizes in the observational studies ranged from 33⁵⁵ to 510⁵² women with DCIS, with three studies including more than 390 women with DCIS.⁵⁰⁻⁵² Sample sizes in the

qualitative studies ranged from 6⁶³ to 34⁶¹ women with DCIS, with three studies including more than 25 women with DCIS.^{49,59,61}

Table 1.4: Measures used in the observational studies in the review

Standardised measures		Non-standardised measures (scales or survey items)	
1.	Hospital Anxiety and Depression Scale (HADS) ^{50,51}	<i>Scales (combined items into summary scores)</i>	
		1.	Perceived Disease Impact Scale (PDIS) ⁵⁵
2.	The Centre for Epidemiologic Studies Depression Scale (CES-D) ^{50,57}	2.	HRQoL scale (physical well-being, sexual adaptation, aesthetic outcome, psychological well-being, relational behaviour, effect on social life, satisfaction with information) ⁵⁸
3.	Revised Impact of Event Scale (RIES) ^{51,57}	3.	Knowledge scale ⁵⁷
		4.	The Breast Cancer Worry Scale (BCWS) ⁵⁷
4.	Rand Medical Outcomes Study: 36-item short form (MOS-SF 36) ^{51,52,55}	<i>Survey items (did not combine items into summary scores)</i>	
		1.	Knowledge ^{55,56}
5.	Rand Medical Outcomes Study Social Support Survey (MOS-SS) ⁵¹	2.	Risk perceptions ^{51,55-57}
		3.	Satisfaction with information ⁵⁷
6.	WHO-Five Well-Being Scale (WHO-5) ⁵⁵	4.	Satisfaction with treatment decision-making ⁵⁷
		5.	Psychological morbidity ⁵⁶
7.	Modifiable Activity Questionnaire ^{53,54}	6.	Type of physician most influential in care ⁵¹
		7.	Satisfaction with communication ^{51,57}
		8.	Satisfaction with care ⁵¹
		9.	Sexuality ⁵⁷
		10.	Physical activity ⁵⁰

3.2C Recruitment of participants

All participants in the observational studies were recruited from hospitals or cancer centres largely via cancer registries, apart from one study which recruited participants from nurses' boards in several states of the USA as part of a large nurse cohort study.⁵² Participants in five of the qualitative studies were recruited from the following sources: a statewide cancer registry,⁶¹ a mammographic screening program,⁵⁹ teaching hospitals,⁶⁴ and cancer

specialists.^{49,63} Two qualitative studies included participants who were self-selected. One study recruited participants through newsletters and advertisements on breast cancer websites,⁶⁰ and one study recruited participants through advertisements with general practitioners, support groups, charities and screening centres.⁶²

3.2D Sample characteristics

Seven studies were conducted in the USA, three studies in Australia, two studies in Canada, two studies in the UK, and two studies in the Netherlands. Most studies included majority-Caucasian samples.⁴⁹⁻⁵⁷ One study included a Latin-American sample,⁶¹ and one study included a Chinese-Canadian sample.⁵⁹ One study recruited women from Italian institutions but did not report any other information about ethnicity,⁵⁸ and four qualitative studies did not report ethnicity data.^{60,62-64} Participants ranged in age from less than 30 years old to more than 80 years old.

3.2E Assessments

All participants in the observational studies were assessed via self-completed or telephone surveys, apart from participants in two longitudinal cohort studies who were assessed via in-person interviews.^{53,54} All participants in the qualitative studies were assessed via interviews, apart from participants in one study who were assessed via focus groups.⁴⁹

In the cross-sectional studies, participant assessments ranged from less than four months after treatment⁵⁶ to a median 4.5 years after treatment.⁵⁸ In two longitudinal cohort studies^{50,51} (which included the same cohort) participants were assessed three times: within six months of the diagnosis, nine months after the initial assessment, and 18 months after the initial assessment. In two other longitudinal cohort studies^{53,54} (which included the same cohort) participants were assessed twice: 4-12 months post-diagnosis (baseline visit), and two years after the baseline visit. In one longitudinal cohort study, participants were assessed three times, four years apart, unrelated to their diagnosis.⁵² There was a wide range of time since diagnosis among participants in most of the qualitative studies. Overall,

the time since diagnosis of participant assessments in the qualitative studies ranged from eight months to 14 years.

3.3 Study quality and methodological limitations

Study quality and methodological limitations of the studies included in the review are discussed below. *Table 1.5 (see Page 39)* also includes information about the attributes and limitations of each study using the lists of criteria developed for the review for appraising the quality of observational and qualitative studies (*see Methods, Table 1.2 & 1.3 Page 22 & Page 24*).

3.3A Observational studies

Overall, the quality of observational studies in the review was good. However, there were some methodological issues that affected the quality of the studies. These issues are discussed below.

The psychometric qualities of the non-standardised measures (that is, the measures that were not previously tested for reliability and validity) are discussed in this section. Studies that included non-standardised scales (which were intended to be combined into summary scores) were examined for reporting of test-retest reliability, internal consistency, and validity (including content, criterion, and construct validity). Studies that included survey items that were not intended to be combined into summary scores as scales were examined for reporting of test-retest reliability and content validity of the survey items.

All studies in the review included non-standardised measures apart from three studies,⁵²⁻⁵⁴ as highlighted in *Table 1.4, Page 32*. Three non-standardised scales (which were intended to be combined into summary scores) were used in the studies in the review, including the HRQoL (Health-Related-Quality-of-Life) scale,⁵⁸ the Perceived Disease Impact Scale (PDIS),⁵⁵ and the Knowledge Scale.⁵⁷ However, none of the studies which included non-standardised scales adequately demonstrated the reliability and validity of the scales.

Amichetti *et al* reported test-retest reliability data for the HRQoL scale, but no internal consistency data.⁵⁸ In addition, Amichetti *et al* only partly assessed content validity (that is, the extent to which a measure has captured the full scope of the construct's domain assessed by an evaluation by expert intended users and target audience³⁶) by developing the scale with "patients with different cancers". However, the study did not report whether women with DCIS were involved in the development of the scale. Amichetti *et al* assessed construct validity of the scale (that is, demonstrating the relationships between the concepts under study and the relevant construct or theory)⁶⁵ by factor analysis followed by varimax rotation. Factor analysis aids in determining the underlying constructs (or factors), which explain correlations within a set of items.³⁶ The study reported that there was "good separation among the items assessing different domains". However, the study did not report any data from the factor analysis. Furthermore, Amichetti *et al* did not measure the criterion validity of the scale by comparing the scale with other 'gold standard' Health-Related-Quality-of-Life instruments.

Bluman *et al* developed a knowledge scale and reported that the scale was "developed specifically for this study and pretested" but did not report any reliability and validity data.⁵⁷ Similarly, Van Gestal *et al* developed the Perceived Disease Impact Scale (PDIS) but did not report any reliability or validity testing.⁵⁵

Most of the observational studies in the review included survey items that were not intended to be combined into summary scores as scales.^{50,51,55-57} However, test-retest reliability and content validity of the survey items were not adequately demonstrated in any of the studies. Only one study partly assessed content validity by developing the survey items "through consultation with oncologists with expertise in breast cancer".⁵⁶ However, this study did not involve women with DCIS in the development of the survey items. None of the studies demonstrated test-retest reliability of the survey items.

Of particular concern is the lack of reliability and validity of the non-standardised measures of risk perception and cancer worry used in the studies and the appropriateness of these measures for women with DCIS. Risk perceptions and cancer worry were assessed in four

studies.^{51,55-57} Two studies^{51,57} used scales adapted from Lerman *et al*,^{66,67,68} developed for women with invasive breast cancer and two studies^{55,56} used risk perception survey items developed by one of the studies.⁵⁶ The Lerman *et al* scales, used by Partridge *et al* and Bluman *et al*, had been tested for internal consistency but had not been tested for test-retest reliability and had not have not been previously validated.⁶⁷ The risk perception survey items developed Rachovitch *et al* and also used in the study by van Gestal *et al*,⁵⁵ were not assessed for test-rest reliability and content validity. Furthermore, the questions included in all the non-standardised measures of risk perception and cancer worry may not be appropriate for women with DCIS because of the use of the term ‘breast cancer’. This term may not be well understood by women with DCIS. For example, the cancer worry scales adapted from Lerman *et al* included questions such as “How worried are you about getting breast cancer”.⁵⁷ Only Partridge *et al* adapted the Lerman *et al* risk perception scale to women with DCIS by including the terms ‘DCIS’ and ‘invasive breast cancer’.⁵¹ However, terms such as ‘DCIS’ and ‘invasive breast cancer’ may also not be well understood by women with DCIS.

Other potential weaknesses in the studies included small sample sizes for subgroup analysis,⁵⁵⁻⁵⁸ low consent rates,^{50,51,53,54} a lack of reporting of data comparing respondents and non-respondents,^{50-56,58} and a lack of reporting about the reasons given or characteristics described of participants lost to follow-up in the longitudinal cohort studies.⁵⁰⁻⁵² In terms of data analysis, two studies^{57,58} were limited by not using multivariate analysis to adjust for potential confounders.

Some of the studies in the review were also limited by their study design. Cross-sectional studies can only assess outcomes at particular points in time. Only one cross-sectional study assessed women with DCIS during the first year after their diagnosis.⁵⁶ The other cross-sectional studies assessed women at 2-3 years after their diagnosis,⁵⁵ mean 1.9 years after their diagnosis,⁵⁷ and median 4.5 years after their treatment.⁵⁸ The results may be subject to recall bias given the long time since diagnosis of some of the cross-sectional studies;^{55,58} and the results are not generalisable to women in the first year after their diagnosis. Furthermore, only two longitudinal cohort studies (which included the same

cohort of women)^{53,54} and two cross-sectional studies^{55,56} included a comparison group of women with invasive breast cancer, and only one longitudinal cohort study included a comparison group of women without DCIS.⁵²

3.3B *Qualitative studies*

Overall, the quality of qualitative studies in the review was good. However, there were some omissions in the qualitative studies that reduced their quality. Although most studies appeared to be based on phenomenology (that is, identifying, understanding and describing different experiences)⁶⁹ only one study⁶⁰ described the particular qualitative research design or theoretical framework of the study. Of the five studies that did not involve a self-selected sample, three studies^{49,59,61} included information about the number of women who were approached to participate and the number of women who consented to the study. None of the studies included information about why women chose not to take part in the study and only one study⁶¹ discussed the characteristics of respondents and non-respondents. A number of studies did not report characteristics of the sample considered to be important to understand the context of the study such as education,^{60,62-64} treatment,⁶³ age,⁶³ and ethnicity of the sample.^{60,62-64} All the studies had an adequate sample size when evaluated in terms of the study aims, design, depth of analysis and rationale, apart from the study by Brown *et al.*⁶³

Most of the studies clearly reported their findings and presented sufficient data to support the findings. However, two older studies^{63,64} combined the findings and discussion points. In addition, Brown *et al* presented insufficient data to support the findings.⁶³

All of the studies involved multiple researchers in the analysis, apart from one study.⁶³ Two studies^{60,62} also involved participants in the analysis. Although not a limitation of the studies, multiple researchers were involved to achieve 'inter-rater reliability' or 'consensus' and participants were involved for 'member checking' or 'verification of data'. This indicates that the researchers were operating under the paradigm of positivism.³⁷ Under a constructivist or interpretivist paradigm, multiple researchers and participants are involved

in the study to increase the understanding of complex phenomenon rather than to reach agreement among different sources, and it has been suggested that this does not result in a failure of reliability.⁴³ Given that most of the studies were operating under a positivist paradigm, it is unsurprising that reflexivity, that is, the impact of the researcher(s) role, background and views on the aims, study design, data collection or analysis was discussed in only one study.⁶⁴

Only two studies^{49,59} adequately evaluated the transferability of findings to other similar contexts, for example, through a thorough discussion about the type and purpose of the sampling strategy, the sample characteristics and the study location and settings.

Table 1.5: Characteristics of the studies included in review

Year First Author (Country)	Sample size & characteristics	Recruitment & consent rate (CR)/ response rate (RR)	Study design & measures	Timing of assessment(s)	Quality appraisal	
					Attributes	Limitations
2009 Ligibel (USA) ⁵⁰	<p>n (DCIS) =391</p> <p>Age: <50 (37%) 50-65 (47%) >65 (16%) White: 94% Employment: 59% Money for special things: 72% Education: college/uni 61% Breast conserving surgery: 67% Mastectomy: 33% Radiotherapy: 51% Tamoxifen: 44%</p> <p>Eligibility criteria: "Ability to speak and read English or Spanish to the extent necessary to complete the questionnaires"</p>	<p>Women recruited from cancer registry (Dana-Farber/Harvard Cancer Centre) and included four regional hospitals (academic and community-based) in Massachusetts</p> <p>CR/RR: 64% (enrolment) 54% (9 mnths) 52% (18 mnths)</p> <p>No reporting of data comparing respondents and non-respondents.</p>	<p>Longitudinal cohort study (telephone surveys)</p> <p><i>Measures:</i></p> <ul style="list-style-type: none"> The Centre for Epidemiologic Studies Depression Scale (CES-D) Anxiety subscale of Hospital Anxiety and Depression Scale (HADS) Authors developed items for exercise 	<ol style="list-style-type: none"> Enrolment (within 3 months of surgery; median=3.8 mnths) 9 mnths after enrolment 18 mnths after enrolment 	<ul style="list-style-type: none"> Rationale/study aims/study design adequately described Study design assessed prospective changes Participants: eligibility criteria reported; important characteristics reported Sample size: large Recruitment: cancer registry for four hospitals (academic and community-based); CR/RR reported Measurement: standardised scales for anxiety and depression Analysis: adjusted for confounders using multivariate analysis 	<ul style="list-style-type: none"> Study design: no comparison group Sample bias: highly educated sample Recruitment: no reporting of data comparing respondents and non-respondents; low response rates for enrolment and follow-up; no reasons given or characteristics described of participants lost to follow-up Timing of assessments: study did not address potential selection bias: some women at initial assessment had not yet completed surgery and radiotherapy which may have affected physical activity levels Measurement: non-standardised measures for health behaviors ie exercise (no reporting of reliability and validity)
2008 Partridge (USA) ⁵¹	<p>n (DCIS) =487</p> <p>Mean age: 53 yrs Range: 26-89yrs White: 94% Education: college 61% Married/de facto: 69% No comorbid conditions: 59% Grade 1: 23% Grade 2: 40% Grade 3: 38% Mastectomy: 34% Tamoxifen: 43%</p>	<p>Women recruited from cancer registry (Dana-Farber/Harvard Cancer Centre) and included four regional hospitals (academic and community-based) in Massachusetts</p> <p>CR/RR:</p>	<p>Longitudinal cohort study (telephone surveys)</p> <p><i>Measures:</i></p> <ul style="list-style-type: none"> Hospital and Anxiety Scale (HADS) Revised Impact of Event Scale (RIES) 	<ol style="list-style-type: none"> Enrolment (≤6 months after diagnosis: within 3 months of surgery or not yet completed surgery; median=3.8 mnths) 9 mnths after enrolment 	<ul style="list-style-type: none"> Rationale/study aims/study design adequately described Study design assessed prospective changes; compared prediagnosis HRQoL; compared HRQoL scores to population normal scores by age Participants: eligibility 	<ul style="list-style-type: none"> Study design: no comparison group Sample bias: highly educated sample Recruitment: no reporting of data comparing respondents and non-respondents; low response rates for enrolment and follow-up; no reasons given or characteristics described of participants lost to follow-up

Year First Author (Country)	Sample size & characteristics	Recruitment & consent rate (CR)/ response rate (RR)	Study design & measures	Timing of assessment(s)	Quality appraisal	
					Attributes	Limitations
	Radiation: 50% Eligibility criteria: “Ability to speak and read English or Spanish to the extent necessary to complete the questionnaires”	64% (enrolment) 54% (9 mnths) 52% (18 mnths) No reporting of data comparing respondents and non-respondents.	<ul style="list-style-type: none"> • Rand Medical Outcomes Study: 36-item short form (MOS-SF 36) • Rand Medical Outcomes Study Social Support Survey (MOS-SS) • Adapted scale for risk perceptions from Lerman <i>et al</i> • Authors developed items to measure type of physician most influential in care; satisfaction with communication; and satisfaction with care 	3. 18 mnths after enrolment	<p>criteria reported; important characteristics reported</p> <ul style="list-style-type: none"> • Sample size: large • Recruitment: cancer registry for four hospitals (academic and community-based); CR/RR reported • Measurement: standardised scales for anxiety and depression; intrusive or avoidant thoughts; HRQoL; and social support; adapted risk perceptions scale for DCIS women • Analysis: adjusted for confounders using multivariate analysis 	<ul style="list-style-type: none"> • Timing of assessments: study did not address potential selection bias: some women at initial assessment had not yet completed surgery and radiotherapy which may have affected physical activity levels • Measurement: non-standardised measures for satisfaction with communication and satisfaction with care (no reporting of reliability and validity); prediagnosis HRQoL was measured by women’s recall at enrolment
2008 Wong (Canada) ⁵⁹	<p>n (DCIS)=26</p> <p>Age: Mean: 52.2 yrs (SD 6.8)</p> <p><i>Country of origin:</i></p> <p>Hong Kong: 50%</p> <p>Mainland China: 38.5%</p> <p>Philippines: 3.8%</p> <p>Taiwan: 3.8%</p> <p>Brunei: 3.8%</p> <p><i>Language for interview:</i></p> <p>Cantonese: 65.4%</p> <p>Mandarin: 26.9%</p> <p>English: 7.7%</p> <p>Time in Canada: M=15.9 yrs (SD 9.4)</p> <p>Married: 88.5%</p> <p>Education: Diploma or degree: 26.9%</p>	<p>Women who self-identified as Chinese who attended Screening Mammography Program of British Columbia (SMPBC) in an urban part of BC</p> <p>CR/RR=70%</p>	Qualitative study (thematic content analysis of semi-structured interviews)	1-2 yrs after surgery	<ul style="list-style-type: none"> • Rationale/study aims/study design adequately described • Participants: eligibility criteria reported; important characteristics reported • Sampling strategy described and justified • Reported CC/RR • Sample size appropriate • Women were interviewed in their language of choice (Cantonese, Mandarin, 	<ul style="list-style-type: none"> • Particular qualitative research design or theoretical framework was not described • Context: no reporting of why people chose not to take part; no comparing or discussion about respondents and non-respondents • No reporting of the impact of the researcher’s role, background and views (reflexivity)

Year First Author (Country)	Sample size & characteristics	Recruitment & consent rate (CR)/ response rate (RR)	Study design & measures	Timing of assessment(s)	Quality appraisal	
					Attributes	Limitations
	Family history: 23.1% Lumpectomy: 42.3% Mastectomy: 57.7%				English) <ul style="list-style-type: none"> • Data collection methods adequately described • Interviews audio-taped and transcribed and translated into English. Inter-rater reliability of translation • Processes of analysis adequately described • Multiple researchers involved in analysis • Sufficient data presented to support the findings • Range of responses captured • Conclusions justified • Critical evaluation of the transferability of findings to other similar contexts made • Relevance of the findings to current knowledge, policy, and practice or to current research discussed 	
2008 Kennedy (UK) ⁶⁰	n (DCIS)= 16 Age: Mean 52.5yrs Range 39-74 years Time since diagnosis: Mean 3.4 years Range 8 months-9 years Married: 69% Mastectomy: 63% Breast conserving surgery: 38%	Women self-selected through newsletters and advertisements on breast cancer websites CR/RR: N/A (self-selected)	Qualitative study (thematic content analysis of semi-structured interviews)	Mean: 3.4 years Range: 8 months to 9 yrs	<ul style="list-style-type: none"> • Rationale/study aims/study design adequately described • Particular qualitative research design or theoretical framework was described: phenomenology • Participants: eligibility 	<ul style="list-style-type: none"> • Participants: no reporting of education, ethnicity • No reporting of the impact of the researcher(s) role, background and views (reflexivity) • Greater discussion needed to critically evaluate the transferability of findings to

Year First Author (Country)	Sample size & characteristics	Recruitment & consent rate (CR)/ response rate (RR)	Study design & measures	Timing of assessment(s)	Quality appraisal	
					Attributes	Limitations
					criteria reported; some important characteristics reported <ul style="list-style-type: none"> • Sampling strategy described and justified • Sample size appropriate • Data collection methods adequately described • Interviews audio-taped and processes of analysis adequately described • Multiple researchers involved in analysis • Participants involved in the analysis • Sufficient data presented to support the findings • Range of responses captured • Conclusions justified • Relevance of the findings to current knowledge, policy, and practice or to current research discussed 	other similar contexts; eg greater discussion of the sample such as the purpose or implications of the large range of time since diagnosis (8mnths-9yrs), and the sample being self-selected through breast cancer websites
2007 van Gestel (Netherlands) ⁵⁵	n (DCIS)= 33 Age: Mean 61yrs Range: <50: to 70+: Married: 88% Education: College 21% No comorbid conditions: 58% Breast conserving surgery: 58% Sentinel node biopsy: 58% Radiotherapy: 56% Chemotherapy: 0% Hormonal therapy: 0%	Women recruited from cancer registry (Eindhoven) and included three community hospitals CR/RR: 75% No reporting of data comparing	Cross-sectional study (self-completed survey) <i>Measures:</i> <ul style="list-style-type: none"> • Rand Medical Outcomes Study: 36-item short form (MOS-SF 36) 	2-3 years after treatment	<ul style="list-style-type: none"> • Rationale/study aims/study design adequately described • Study design: included a comparison group of invasive breast cancer women; also compared results with general population normal scores by age 	<ul style="list-style-type: none"> • Sample size of DCIS women: small • Recruitment: no reporting of data comparing respondents and non-respondents • Timing of assessment: no short-term data • Measurement: non-standardised measures for disease impact; risk perceptions; and

Year First Author (Country)	Sample size & characteristics	Recruitment & consent rate (CR)/ response rate (RR)	Study design & measures	Timing of assessment(s)	Quality appraisal	
					Attributes	Limitations
	<p>n (invasive breast cancer)= 91 No axillary node dissection No significant differences in age, education, comorbidity to DCIS women Significantly more likely to have breast conserving surgery, sentinel node biopsy, radiotherapy, chemotherapy, hormonal therapy</p> <p>Eligibility criteria: excluded “non-Dutch speaking patients”</p>	<p>respondents and non-respondents.</p>	<ul style="list-style-type: none"> • WHO-Five Well-Being Scale (WHO-5) • Authors developed Perceived Disease Impact Scale (PDIS) • Adapted scale/items for risk perceptions and understanding of the diagnosis from Rakovitch <i>et al</i> 		<ul style="list-style-type: none"> • Participants: eligibility criteria reported; important characteristics of DCIS group and comparison group reported • Recruitment: cancer registry for three hospitals (community-based); CR/RR reported and adequate • Measurement: standardised scales for HRQoL; and well being • Analysis: compared characteristics of DCIS and invasive groups; adjusted for treatment differences between groups using multivariate analysis 	<p>understanding of the diagnosis (no reporting of reliability and validity)</p>
2007 Napoles-Springer (USA) ⁶¹	<p>n (DCIS)= 34 Latina women: n=16 Non-Latina women: n=18 Women with previous DCIS or breast cancer not excluded.</p> <p>Overall: Age: Mean 60.5 yrs SD 11.0; Range 40-49 to ≥70 years Married/de facto: 69.7% Education: college 35% Mastectomy: 38% Breast conserving surgery: 59% Radiotherapy: 26%</p>	<p>Women recruited from statewide cancer registry</p> <p>CC/RR: 31%</p> <p>No statistically significant differences between respondents and non-respondents on age, time since diagnosis, tumor grade, country of residence</p>	<p>Qualitative study (thematic content analysis of semi-structured interviews)</p>	<p>1-4 years after diagnosis</p>	<ul style="list-style-type: none"> • Rationale/study aims/study design adequately described • Participants: eligibility criteria reported; important characteristics reported • Participants: included Latina women • Sampling strategy described and justified • Reported CC/RR and compared respondents with non-respondents on 	<ul style="list-style-type: none"> • Particular qualitative research design or theoretical framework was not described • Context: no reporting of why people chose not to take part • No reporting of the impact of the researcher(s) role, background and views (reflexivity) • Greater discussion needed to critically evaluate the transferability of findings to other similar contexts; no discussion about such as the

Year First Author (Country)	Sample size & characteristics	Recruitment & consent rate (CR)/ response rate (RR)	Study design & measures	Timing of assessment(s)	Quality appraisal	
					Attributes	Limitations
	<p>Hormonal therapy: 47%</p> <p>Non-Latina Whites were significantly more likely to report a college education than Latina women; and to not have high grade tumors. No significant differences on age, age at diagnosis, marital status, treatment.</p>				<p>important characteristics</p> <ul style="list-style-type: none"> • Sample size appropriate • Women were interviewed in their language of choice (English or Spanish) • Data collection methods adequately described • Interviews audio-taped and transcribed and translated if necessary • Processes of analysis adequately described • Multiple researchers involved in analysis • Sufficient data presented to support the findings • Range of responses captured • Conclusions justified • Relevance of the findings to current knowledge, policy, and practice or to current research discussed 	<p>purpose or implications of the large range of time since diagnosis (1-4yrs), the higher education of non-Latina women compared to the Latina women, and not excluding women with previous breast cancer</p>
2006 Nekhlyudov (USA) ⁵²	<p>n (DCIS)= 510</p> <p>Enrolled nurses: 100%</p> <p>Age: Mean: 52.4 yrs (10.5 SD)</p> <p>Breast conserving surgery: 54%</p> <p>Radiotherapy: 41%</p> <p>Tamoxifen therapy: 34%</p> <p>BMI: 25.8</p> <p>Mean physical activity: 18.5</p> <p>Post menopausal: 92.9%</p>	<p>Women recruited from nursing boards in 11 states in USA for Nurses Health Surveys</p> <p>NHS1: originated 1976</p> <p>NHS: originated 1989</p>	<p>Longitudinal cohort study (self-completed surveys)</p> <p><i>Measures:</i></p> <ul style="list-style-type: none"> • Rand Medical Outcomes Study: 36-item short form (MOS-SF 36) 	<p>Women surveyed every 4 years (1992, 1996; 2000)</p>	<ul style="list-style-type: none"> • Rationale/study aims/study design adequately described • Study design assessed prospective changes; included a comparison group of women without DCIS; assessed and adjusted for pre-illness physical and 	<ul style="list-style-type: none"> • Participants: no reporting of ethnicity • Sample bias: registered nurses (greater access to information and support about their diagnosis) • Recruitment: no reporting of data comparing respondents and non-respondents; no follow-up CR/RR reported, no reasons

Year First Author (Country)	Sample size & characteristics	Recruitment & consent rate (CR)/ response rate (RR)	Study design & measures	Timing of assessment(s)	Quality appraisal	
					Attributes	Limitations
	<p>Hormonal therapy ?for menopause: 38.5% Alcohol: 56.8% Smoking: 11.6% Family history of breast cancer: 18.2% ≥ 1 comorbid condition: 51.8%</p> <p>n (women free of DCIS ie without cancer)=114,218 DCIS Enrolled nurses 100% No significant differences to women with DCIS in BMI, mean physical activity, post menopausal, hormonal therapy, alcohol, smoking, ≥ 1 comorbid condition. Significantly different to women with DCIS in age (mean 47.8yrs SD11.5yrs); and family history of breast cancer. (Study adjusted for age differences by normalizing the remaining characteristics to age 60.)</p>	<p>CR/RR: 94% (enrolment) not sure for other dates</p> <p>No reporting of data comparing respondents and non-respondents.</p>			<p>psychological function</p> <ul style="list-style-type: none"> Participants: eligibility criteria reported; important characteristics of DCIS group and comparison group reported Sample size: large Recruitment: Nurse Health Surveys; CR/RR reported for enrolment and good Timing of assessments: long follow-up period Measurement: standardised scale for HRQoL Analysis: compared characteristics of DCIS women and women without DCIS; adjusted for differences eg age; adjusted for confounders using multivariate analysis 	<p>given or characteristics described of participants lost to follow-up</p>
2006 Prinjha (UK) ⁶²	<p>n (DCIS)= 10</p> <p>Age at interview: Range: 52-69yrs Age at diagnosis: Range: 49-60yrs Mastectomy: 99% Time since diagnosis: 1-14yrs “Maximum variation sample to include younger and older women from various social background.”</p>	<p>Women self-selected through advertisements with general practitioners, support groups, charities and screening centres for a health website</p> <p>CR/RR: N/A (self-</p>	Qualitative study (thematic content analysis of open-ended interviews)	1-14 years after diagnosis	<ul style="list-style-type: none"> Rationale/study aims/study design adequately described Participants: eligibility criteria reported; some important characteristics reported Sampling strategy described and justified Data collection methods 	<ul style="list-style-type: none"> Particular qualitative research design or theoretical framework was not described Sample size small (DCIS women comprised a small subset of sample for study) Participants: no reporting of education, ethnicity No reporting of the impact of the researcher(s) role,

Year First Author (Country)	Sample size & characteristics	Recruitment & consent rate (CR)/ response rate (RR)	Study design & measures	Timing of assessment(s)	Quality appraisal	
					Attributes	Limitations
		selected)			adequately described • Interviews audio-taped and transcribed • Processes of analysis adequately described • Multiple researchers involved in analysis • Participants involved in the analysis • Sufficient data presented to support the findings • Range of responses captured • Conclusions justified • Relevance of the findings to current knowledge, policy, and practice or to current research discussed	background and views (reflexivity) • Greater discussion needed to critically evaluate the transferability of findings to other similar contexts eg such as the purpose or implications of almost all women having mastectomy, the large range of time since diagnosis: 1-14yrs of participants, self-selected sample through a health website
2005 Irwin (USA) ⁵³	n (DCIS)=129 n (invasive breast cancer)= 385 Characteristics (DCIS & invasive breast cancer) Age: Mean 56.3 (10.5 SD) Education: 98% high school graduates Postmenopausal at baseline: 69% Ethnicity 85% non-Hispanic white; 15%Hispanic white Surgery only 30% Surgery plus radiotherapy 42% Chemotherapy 27%	Women recruited to the HEAL Study through the Surveillance, Epidemiology, and End Results (SEER) registries in New Mexico and Western Washington. CR/RR: 42% of those enrolled in HEAL study participated No reporting of data comparing	Longitudinal cohort study (in-person interviews) <i>Measures:</i> • BMI • Body (body scans) • Modifiable Activity Questionnaire	• 4-12 months post-diagnosis (baseline visit) • 2 years after the baseline visit	• Rationale/study aims/study design adequately described • Study design assessed prospective changes; included a comparison group of women with invasive breast cancer; assessed prediagnosis body fat and weight changes • Participants: eligibility criteria reported; important characteristics of sample reported • Sample size: large	• Recruitment: low CR/RR; no reporting of data comparing respondents and non-respondents. • Sample bias: highly educated sample • Timing of assessments: study did not address potential selection bias: some women at initial assessment had not yet had or had not yet completed treatment and therefore some women may have already experienced weight or body fat changes at baseline • Pre-diagnosis BMI or body fat

Year First Author (Country)	Sample size & characteristics	Recruitment & consent rate (CR)/ response rate (RR)	Study design & measures	Timing of assessment(s)	Quality appraisal	
					Attributes	Limitations
	Tamoxifen 48%	respondents and non-respondents.			<ul style="list-style-type: none"> Recruitment: CR/RR reported for enrolment; reasons given for participants lost to follow-up Measurement: standardised scale for physical activity Analysis: adjusted for confounders using multivariate analysis 	levels not available
2003 Irwin (USA) ⁵⁴	<p>n (DCIS)=185</p> <p>n (invasive breast cancer)= 627</p> <p>Characteristics (DCIS & invasive breast cancer)</p> <p>Age: Mean 52.4 (10.5 6.4)</p> <p>Education: 98% high school graduates</p> <p>Postmenopausal at baseline: 56%</p> <p>Ethnicity</p> <p>White 90%</p> <p>African American 1%</p> <p>American Indian 1%</p> <p>Asian 6%</p> <p>Other 2%</p> <p>Surgery only 26%</p> <p>Surgery plus radiotherapy 41%</p> <p>Chemotherapy 9%</p> <p>Radiotherapy and chemotherapy 24%</p> <p>Tamoxifen 51%</p>	<p>Women recruited to the HEAL Study through the Surveillance, Epidemiology, and End Results (SEER) registries in New Mexico and Western Washington.</p> <p>CR/RR: 69% of those enrolled in HEAL study participated</p> <p>No reporting of data comparing respondents and non-respondents.</p>	<p>Longitudinal cohort study (in-person interviews)</p> <p><i>Measures:</i></p> <ul style="list-style-type: none"> Modifiable Activity Questionnaire 	<ul style="list-style-type: none"> 4-12 months postdiagnosis (baseline visit) 	<ul style="list-style-type: none"> Rationale/study aims/study design adequately described Study design assessed prospective changes; included a comparison group of women with invasive breast cancer; assessed prediagnosis body fat and weight changes Participants: eligibility criteria reported; important characteristics of sample reported Sample size: large Recruitment: CR/RR reported for enrolment; reasons given for participants lost to follow-up Measurement: standardised scale for physical activity 	<ul style="list-style-type: none"> Recruitment: low CR/RR; no reporting of data comparing respondents and non-respondents. Sample bias: highly educated sample Timing of assessments: study did not address potential selection bias: some women at initial assessment had not yet had or had not yet completed treatment which may have affected physical activity levels Measurement: prediagnosis physical activity levels were measured by women's recall at enrolment

Year First Author (Country)	Sample size & characteristics	Recruitment & consent rate (CR)/ response rate (RR)	Study design & measures	Timing of assessment(s)	Quality appraisal	
					Attributes	Limitations
2003 Rakovitch (Canada) ⁵⁶	<p>n (DCIS)= 64</p> <p>Age: Mean 56yrs Range 35-81yrs Breast conserving surgery: 100% Axillary dissection: 18.8% Tamoxifen: 8%</p> <p>n (invasive breast cancer)= 164</p> <p>No significant difference in age: Mean 58.2yrs Range 25-90yrs Breast conserving surgery: 100% Axillary dissection: 90% Tamoxifen: 35% Chemotherapy: 19% Node positive: 0%</p> <p>Eligibility criteria: excluded women who “did not understand English”</p>	<p>Women (consecutive patients) recruited from a tertiary referral cancer centre.</p> <p>CR/RR: 95%</p> <p>No reporting of data comparing respondents and non-respondents.</p>	<p>Cross-sectional study (self-completed survey)</p> <p><i>Measures:</i></p> <ul style="list-style-type: none"> Authors developed items for risk perception; understanding of the diagnosis; psychological morbidity 	<p>Women were eligible if surgery was ≤ 4 months. Authors report time since diagnosis as: ‘shortly after the surgical procedure.’</p>	<ul style="list-style-type: none"> Analysis: adjusted for confounders using multivariate analysis Rationale/study aims/study design adequately described Study design: included a comparison group of invasive breast cancer women Participants: eligibility criteria reported; some characteristics of DCIS group and comparison group reported Sample size: adequate Recruitment: CR/RR reported and good Measurement: authors developed a DCIS-specific risk perception scale Analysis: compared characteristics of DCIS and invasive groups; clearly explained how missing data was addressed 	<ul style="list-style-type: none"> Participants: no reporting of education levels of DCIS group and comparison group Recruitment: no reporting of data comparing respondents and non-respondents; recruited from only one tertiary cancer centre Measurement: non-standardised measures for psychological morbidity; risk perceptions; and understanding of the diagnosis (no reporting of reliability and limited validity)
2002 De Morgan (Australia) ⁴⁹	<p>n (DCIS)= 26</p> <p>Age: Range: 40-49 yrs to ≥70yrs Education: 46% college Married/de facto: 92% Employed 46%</p>	<p>Consecutive sample of the most recently diagnosed women with DCIS recruited through 7 clinicians ie breast surgeons</p>	<p>Qualitative study (thematic content analysis of focus groups)</p>	<p>Time since diagnosis: 6mth-1 yr: 65% 2-3yrs: 23% 4-5yrs:12%</p>	<ul style="list-style-type: none"> Rationale/study aims/study design adequately described Participants: eligibility criteria reported; some important characteristics 	<ul style="list-style-type: none"> Particular qualitative research design or theoretical framework was not described Context: no reporting of why people chose not to take part; no comparing or discussion about

Year First Author (Country)	Sample size & characteristics	Recruitment & consent rate (CR)/ response rate (RR)	Study design & measures	Timing of assessment(s)	Quality appraisal	
					Attributes	Limitations
	Time since diagnosis: 6mth-1 yr: 65% 2-3yrs: 23% 4-5yrs: 12% First language not English: n=1 Rural: n=5 Urban: n=21 Aboriginal: n=1	and radiation oncologists CC/RR=74% No reporting of data comparing respondents and non-respondents.			<ul style="list-style-type: none"> reported • Sampling strategy described • Data collection methods adequately described • Interviews audio-taped and transcribed • Processes of analysis adequately described • Multiple researchers involved in analysis • Sufficient data presented to support the findings • Range of responses captured • Conclusions justified • Critical evaluation of the transferability of findings to other similar contexts made • Relevance of the findings to current knowledge, policy, and practice or to current research discussed 	<ul style="list-style-type: none"> respondents and non-respondents • Participants: no reporting of treatment (only in findings) • No reporting of the impact of the researcher(s) role, background and views (reflexivity)
2001 Bluman (USA) ⁵⁷	n (DCIS)= 76 Age: mean 56 yrs range: 33-82yrs Ethnicity: 91% white Married/de facto: 72% Education: 59% college Treatment: BCS: 31% Mastectomy: 68% Breast conserving surgery: 31% Radiotherapy: 26%	Women recruited from cancer registry at academic breast clinic CC=79% RR= 62% Statistically significant	Cross-sectional study (self-completed survey) <i>Measures:</i> <ul style="list-style-type: none"> • Revised Impact of Event Scale (RIES) • Centre for Epidemiologic 	Mean: 1.9 years after diagnosis	<ul style="list-style-type: none"> • Rationale/study aims/study design adequately described • Participants: eligibility criteria reported; important characteristics reported • Recruitment: CR/RR reported • Measurement: authors 	<ul style="list-style-type: none"> • Study design: lack of a comparison group of women with invasive breast cancer or women from the general population; no short term data available (mean 1.9 years) • Sample size: small (for subgroup analysis) • Recruitment: one academic breast clinic; RR low

Year First Author (Country)	Sample size & characteristics	Recruitment & consent rate (CR)/ response rate (RR)	Study design & measures	Timing of assessment(s)	Quality appraisal	
					Attributes	Limitations
		differences between respondents and non-respondents on time since diagnosis (non-respondents 3.5yrs vs respondents 1.9yrs) and age (63yrs vs 56 yrs).	Studies Depression Scale (CES-D) <ul style="list-style-type: none"> • adapted The Breast Cancer Worry Scale (BCWS) • Adapted risk perceptions items from Lerman <i>et al</i> • Authors developed a knowledge scale • Authors developed items for satisfaction with communication and information; treatment decision-making; sexual function. 		developed a DCIS-specific knowledge scale; standardised scales for intrusive thoughts about cancer; and depression <ul style="list-style-type: none"> • Analysis: compared characteristics of respondents and non-respondents 	<ul style="list-style-type: none"> • Timing of assessment: did not report the range of time since diagnosis • Measurement: non-standardised measures for knowledge (Authors reports “scale pretested” but does not include any data about reliability and validity testing); and satisfaction with communication, information and treatment decision-making; and sexual function (no reporting of reliability and validity); limited assessment of satisfaction with information and treatment decision-making; risk perceptions and cancer worry scales not DCIS-specific • Analysis: did not adjust for differences in respondents and non-respondents eg time since diagnosis and age; no reporting of p values and exact variable categories used for testing associations; used univariate analysis only (not multivariate analysis) to test associations; no reporting of mean RIES (SD)
2000 Brown (Australia) ⁶³	n (DCIS)= 6 Time since surgery: 6mth-2yrs (n=5) 4yrs (n=1)	Women recruited through one breast surgeon at a teaching hospital (South Australia) No reporting of	Qualitative study (thematic content analysis of semi-structured interviews)	Time since surgery: 6mth-2yrs (n=5) 4yrs (n=1)	<ul style="list-style-type: none"> • Rationale/study aims/study design adequately described • Participants: eligibility criteria reported • Sampling strategy 	<ul style="list-style-type: none"> • Particular qualitative research design or theoretical framework was not described • Participants: important characteristics not reported eg age, education, ethnicity,

Year	Sample size & characteristics	Recruitment & consent rate (CR)/ response rate (RR)	Study design & measures	Timing of assessment(s)	Quality appraisal	
First Author (Country)					Attributes	Limitations
		CC/RR No reporting of data comparing respondents and non-respondents.			described <ul style="list-style-type: none"> • Data collection methods adequately described • Interviews audio-taped and transcribed • Processes of analysis adequately described • Range of responses captured • Conclusions justified • Relevance of the findings to current knowledge, policy, and practice or to current research discussed 	treatment <ul style="list-style-type: none"> • Context: no reporting of how many women were approached; how many women refused and why people chose not to take part; no comparing or discussion about respondents and non-respondents • Sample size small for depth of analysis • Sampling strategy inadequately justified • Unclear whether multiple researchers were used in the analysis • Insufficient data presented to support the findings • Unclear reporting of the findings due to combining the findings and discussion points • No reporting of the impact of the researcher(s) role, background and views (reflexivity) • No discussion to critically evaluate the transferability of findings to other similar contexts such as the purpose or implications of women being recruited through one surgeon, the nature of the location and setting; and of the sample characteristics
1998 Amichetti	n (DCIS)= 83	Women recruited from 6 medical	Cross-sectional study (self-completed	Median time after treatment (54.5	<ul style="list-style-type: none"> • Rationale/study aims/study design 	<ul style="list-style-type: none"> • Study design: lack of a comparison group of women

Year First Author (Country)	Sample size & characteristics	Recruitment & consent rate (CR)/ response rate (RR)	Study design & measures	Timing of assessment(s)	Quality appraisal	
					Attributes	Limitations
(Netherlands) ⁵⁸	Age: median 54 yrs Range 29-88 yrs Married/de facto: 75% Education: University/college 5% Employment: 30%	institutions in Italy CR/RR: 78% No reporting of data comparing respondents and non- respondents.	survey) <i>Measures:</i> Authors developed HRQoL scale measuring physical well-being, sexual adaptation, aesthetic outcome, psychological well- being, relational behaviour, effect on social life, satisfaction with information <i>Testing:</i> Reliability 0.76 correlation coefficient; construct validity evaluated by factor analysis followed by varimax rotation	months)	adequately described • Participants: eligibility criteria reported; important characteristics reported • Recruitment: 6 medical institutions; CR/RR reported and adequate • Measurement: scale developed by authors (internal reliability adequate)	with invasive breast cancer or women from the general population; no short term data available (median 54.5 months after treatment) • Sample size: small (for subgroup analysis) • Participants: women had low education levels • Recruitment: no reporting of data comparing respondents and non-respondents • Timing of assessment: did not report the range of time since diagnosis • Measurement: non-standardised measures of HRQoL • Analysis: no reporting of p values and exact variable categories used for testing associations; used univariate analysis only (not multivariate analysis) to test associations
1997 Webb (Australia) ⁶⁴	n (DCIS)= 10 Age: Mean 66.1 yrs Range: 55-81 yrs Married: 40% Ethnicity: “first, second, later generation immigrants from a variety of cultures including German, English and Italian.” Treatment: Breast conserving surgery: 80% Mastectomy: 20%	Women recruited from two teaching hospitals in different parts of a major city (Adelaide). No reporting of CC/RR No reporting of data comparing respondents and non-	Qualitative study (thematic content analysis of open- ended interviews)	Time since diagnosis: Range: 3 mnths-1 year	• Rationale/study aims/study design adequately described • Participants: eligibility criteria reported; some important characteristics reported • Sampling strategy described • Sample size partly justified by “categories were well developed and	• Particular qualitative research design or theoretical framework was not described • Participants: important characteristics not reported eg education; and unclear reporting of ethnicity • Context: no report of how many women were approached; how many women refused and why people chose not to take part; no comparing or discussion about

Year	Sample size & characteristics	Recruitment & consent rate (CR)/ response rate (RR)	Study design & measures	Timing of assessment(s)	Quality appraisal	
First Author						
(Country)					<i>Attributes</i>	<i>Limitations</i>
		respondents.			<p>little new was added after 10"</p> <ul style="list-style-type: none"> • Data collection methods adequately described • Interviews audio-taped and transcribed • Processes of analysis adequately described • Multiple researchers involved in analysis • Sufficient data presented to support the findings • Range of responses captured • Reporting of the impact of the researcher(s) role, background and views (reflexivity) • Conclusions justified • Relevance of the findings to current knowledge, policy, and practice or to current research discussed 	<p>respondents and non-respondents</p> <ul style="list-style-type: none"> • Sample size small due to 'lack of time' • Unclear reporting of the findings due to combining the findings and discussion points • Greater discussion needed to critically evaluate the transferability of findings to other similar contexts such as such as the purpose or implications of the sample characteristics

3.4 The experiences of women diagnosed with DCIS

The data were synthesised into nine themes and 27 subthemes using thematic analysis as described in the *Methods* (see Page 26). The themes and subthemes are shown in *Table 1.6*. The nine themes included *knowledge; information needs; treatment decision-making; psychological morbidity; sexuality; relationships, social support and functioning; physical health; benefits of the diagnosis; and experiences of women with DCIS from culturally and linguistically diverse (CALD) backgrounds*. *Table 1.6* also highlights the themes and subthemes that were identified in both the quantitative and qualitative data, in the quantitative data only, and in the qualitative data only.

Table 1.6: Themes and subthemes developed from the data

Themes		Subthemes	
1	Knowledge	i	Description of the diagnosis
		ii	DCIS-related risk perceptions
		iii	Risk perceptions and psychological morbidity
		iv	Risk perceptions and other participant characteristics
		v	Knowledge about the natural history of DCIS
		vi	Knowledge of DCIS prior to the diagnosis
2	Information needs	i	Satisfaction with information
		ii	Sources of information
		iii	Methods to increase women's understanding and recall
		iv	Information at mammographic screening

continued next page

Key



Theme or subtheme identified in the quantitative & qualitative data



Theme or subtheme identified in the quantitative data only



Theme or subtheme identified in the qualitative data only

Themes		Subthemes	
3	Treatment decision-making	i	Satisfaction with treatment decision-making
		ii	Difficulties experienced in treatment decision-making
		iii	Factors influencing treatment decisions
		iv	Perceived level of involvement in treatment decision-making
4	Psychological morbidity	i	Confusion relating to the diagnosis
		ii	Psychological distress and well-being
		iii	Cancer-specific worry
		iv	Impact of asymptomatic disease
		v	Communication and support from clinicians
		vi	Support groups
5	Sexuality		
6	Relationships, social support and functioning	i	Interpersonal relationships
		ii	Social support
		iii	Social functioning
7	Physical health	i	Physical health and functioning
		ii	Physical activity and weight gain
8	Benefits of the diagnosis		
9	Experiences of women with DCIS from culturally and linguistically diverse (CALD) backgrounds	i	Latina American women
		ii	Chinese Canadian women

The review findings in each theme and subtheme are described below. *Table 1.7* (see Page 78) highlights the key findings from the review and the supporting evidence for each key finding.

3.4.1 Knowledge

One large longitudinal cohort study,⁵¹ three smaller cross-sectional studies,⁵⁵⁻⁵⁷ and six qualitative studies^{49,60-64} explored women's knowledge about their diagnosis.

3.4.1A Description of the diagnosis

None of the quantitative studies assessed how women described their diagnosis. Kennedy *et al* and De Morgan *et al* in qualitative studies found that the terms women used to describe their diagnosis varied greatly and included early breast cancer, a 'contained' non-invasive breast cancer, not a 'real' breast cancer ("You fall between normal and cancer"), a pre-cancer, and a benign condition.^{49,60} Prinjha *et al* found that half of the women with DCIS thought they had invasive breast cancer, and Brown *et al* and Webb *et al* (in older studies) found that most women thought they had invasive breast cancer ("They said it was definitely cancer, very early").⁶²⁻⁶⁴ In contrast, Napoles-Springer *et al* found that most of the non-Latina white women in the study described their diagnosis as a 'contained' non-invasive breast cancer.⁶¹

3.4.1B DCIS-related risk perceptions

Women's DCIS-related risk perceptions were assessed in one large longitudinal cohort study⁵¹ and three smaller cross-sectional studies using non-standardised measures.⁵⁵⁻⁵⁷ Partridge *et al* in a longitudinal cohort study found that women with DCIS overestimated their risk of local and distant recurrence and dying from breast cancer and that inaccurate risk perceptions did not change over time.⁵¹ The study found that 39% of women perceived at least a moderate risk for invasive breast cancer in the next 5 years, 53% in their lifetime; and 28% of DCIS spreading to other places in the body, when surveyed within six months

of their diagnosis. The mean perceived risk did not significantly change at nine months and 18 months after the initial assessment. Van gestalt *et al* and Rakovitch *et al* in cross-sectional studies involving women with DCIS and invasive breast cancer found that women with DCIS had similar risk perceptions of local and distant recurrence and dying from breast cancer as women with invasive breast cancer.^{55,56} Van Gestal *et al* surveyed women 2-3 years after treatment and found that the mean risk perception was 24% that 'breast cancer would re-appear in the same breast', 14% that 'cancer would appear somewhere else in your body', and 15% that 'you will die of breast cancer'.⁵⁵ Rakovitch *et al* surveyed women shortly after surgery and found that 53% of women thought that it was 'likely' or 'very likely' that 'breast cancer would re-appear in the same breast', 36% that 'breast cancer would appear somewhere else in your body, and 27% that 'you will die of breast cancer'.⁵⁶ Bluman *et al*, in a cross-sectional study, that involved only women with DCIS, also found a high proportion of women with inaccurate risk perceptions.⁵⁷ Bluman *et al* surveyed women 1.9 years (mean) after their diagnosis and found that 78% of women did not know that DCIS could not metastasize, 33% said that it was 'likely', 'moderately likely', or 'very likely' that their disease would metastasize, and half of women thought that their risk of developing breast cancer again was 50% or higher.⁵⁷

3.4.1C Risk perceptions and psychological morbidity

Possible associations between DCIS-related risk perceptions about DCIS and psychological morbidity were tested in one large longitudinal cohort study⁵¹ and one smaller cross-sectional study.⁵⁵ Partridge *et al* in a longitudinal cohort study found that overestimated risk perceptions of local recurrence, that is, of DCIS or invasive breast cancer recurring within five years and of invasive breast cancer recurring within the woman's lifetime, were associated with increased anxiety in women with DCIS as measured by the Hospital and Anxiety Scale (HADS).⁵¹ Partridge *et al* also found that the belief in at least a moderate likelihood of DCIS metastasizing was associated with intrusive or avoidant thoughts about the diagnosis as measured by the Revised Impact of Event Scale (RIES) but not with anxiety and depression as measured by the HADS. Van gestalt *et al* in a cross-sectional

study did not find any association between risk perceptions and well-being as measured by the WHO-Five Well-Being Scale (WHO-5).⁵⁵

Six qualitative studies^{49,60-64} also found that women's distress was related to women's understanding of their diagnosis. Women who thought they had a pre-cancer or a 'contained' non-invasive breast cancer were partly reassured by the good prognosis and were less worried about their 'cancer' spreading and causing death than women who thought they had invasive breast cancer.^{49,60,61} However, some women who thought they had early invasive breast cancer were relieved that their disease was detected 'early'.^{60,62-64} Women in the study by Kennedy *et al* also described the shock and distress of the diagnosis for their family, the distress often linked to family members viewing DCIS as invasive breast cancer.⁶⁰

3.4.1D Risk perceptions and other participant characteristics

One large longitudinal cohort study⁵¹ and one smaller cross-sectional study⁵⁷ assessed possible factors associated with overestimated risk perceptions other than psychological morbidity and found that overestimated risk perceptions were not associated with any other factors. Partridge *et al* in a longitudinal cohort study found no associations between overestimated risk perceptions and age, ethnicity, education, marital status, employment, financial status, comorbidity, mental and physical functioning at enrolment (as measured by Medical Outcomes Study SF-36), perception of physician communication, physician primary care, consulting with a medical oncologist, satisfaction with treatment, mastectomy/ radiation received before enrolment, and grade of DCIS using logistic regression analysis.⁵¹ Bluman *et al* in a cross-sectional study did not find any associations between risk perceptions and age, time since diagnosis, and treatment type using univariate analysis.⁵⁷

3.4.1E Knowledge about the natural history of DCIS

None of the quantitative studies explored women's knowledge about the natural history of DCIS including the uncertainty about DCIS progression to invasive breast cancer. Three qualitative studies^{49,60,62} found that only some women with DCIS were aware that not all women would develop invasive breast cancer if untreated.

3.4.1F Knowledge of DCIS prior to the diagnosis

Two qualitative studies^{60,62} found that most women had no prior knowledge about DCIS before their diagnosis and that little information about DCIS was available at mammographic screening. Kennedy *et al* suggested that poor knowledge about DCIS prior to the diagnosis may “intensify the shock and distress” women with DCIS experienced at diagnosis.⁶⁰

See *Table 1.7 (Page 78)* for the key findings related to the theme of **Knowledge**.

3.4.2 Information needs

Two cross-sectional studies^{57,58} and five qualitative studies^{49,60-63} explored aspects of women's information needs.

3.4.2A Satisfaction with information

Two cross-sectional studies^{57,58} and five qualitative studies^{49,60-63} explored women's satisfaction with information with mixed results. The qualitative studies^{49,60-63} highlighted that many women were dissatisfied with the amount of written and verbal information they received specifically about DCIS. Kennedy *et al* highlighted that most women thought that the information about DCIS was “absent, limited or contradictory”.⁶⁰ The qualitative studies highlighted that women wanted more information about the following: what DCIS is and whether it is cancer or not;^{49,60,62} the risk of DCIS developing into invasive breast

cancer or ‘progressing’, including the uncertainties;^{60,62} whether surgery is really necessary when DCIS may not develop into invasive breast cancer;⁶² the pathological findings after surgery, for example, margins and size;⁶² whether ‘cancer’ would recur;⁶³ whether ‘they’d got it all’;⁶³ the risk of a daughter developing breast cancer;⁶³ physical treatment issues;⁶¹ and the roles of the different specialists.⁶¹

Bluman *et al* and Amichetti *et al* in cross-sectional studies found that most women with DCIS were satisfied with the information they received about their diagnosis.^{57,58} However, Bluman *et al* and Amichetti *et al* assessed women’s satisfaction with information broadly and did not assess various aspects of the diagnosis and prognosis. Bluman *et al* found that more than 90% of women were ‘mostly’ or ‘very’ satisfied with the ‘information from doctors’ when surveyed 1.9 years (mean) after their diagnosis.⁵⁷ However, the study also found that approximately one third of women were ‘not satisfied’ or only ‘somewhat satisfied’ with ‘information related to future health problems’. Amichetti *et al* found that 79% of women considered the ‘information about the disease’ sufficient, 75% considered the ‘information about surgery’ sufficient, and 79% considered the ‘information about radiotherapy’ sufficient when surveyed 4.5 years (median) after their treatment.⁵⁸ However, the study was limited by the potential recall bias created by the long time since diagnosis of the survey.

3.4.2B Sources of information

Three qualitative studies^{49,61,63} found that many women considered the most important source of information was their clinician. Satisfaction with information was related to women feeling that they had received thorough explanations from their doctor about aspects of their care and that they could ask their doctor questions.^{49,61,63}

Four qualitative studies^{49,60,62,63} found that many women sought information about their diagnosis from sources other than their treatment team due to their dissatisfaction with the information provided and in response to the unfamiliarity and uncertainty surrounding DCIS. Information sources other than the treatment team included the Internet, journals,

books, and other health professionals. Many women reported dissatisfaction with the information about DCIS on the Internet because they thought that the information was contradictory or confusing.^{49,60,62}

3.4.2C Methods to increase women's understanding and recall

Methods to increase women's understanding and recall about DCIS are demonstrated in two qualitative studies^{60,63} included providing advice about appropriate websites, books or articles for more information about DCIS;⁶⁰ audio-taping consultations⁶³ using diagrams and writing key messages during consultations;⁶³ and encouraging the woman to bring a friend into the consultations.⁶³

3.4.2D Information at mammographic screening

Two qualitative studies^{60,62} found that many women wanted more information about DCIS prior to mammographic screening so that they could be better prepared for the possibility of being diagnosed with DCIS. Prinjha *et al* also found that half of the women in the study felt the omission of information about DCIS at mammographic screening prevented them from making fully informed decisions about whether to attend mammographic screening.⁶²

See *Table 1.7 (Page 78)* for the key findings related to the theme of **Information needs**.

3.4.3 Treatment decision-making

One cross-sectional study⁵⁷ and four qualitative studies^{49,60-62} explored aspects of treatment decision-making in women with DCIS.

3.4.3A Satisfaction with treatment decision-making

One cross-sectional study⁵⁷ and one qualitative study⁶¹ explored women's satisfaction with treatment decision-making. Bluman *et al* in a cross-sectional study found that more than

90% of women were satisfied with their ‘choice of treatment’ and ‘the ability to make treatment decisions’ when surveyed 1.9 years (mean) after their diagnosis using a non-standardised measure.⁵⁷ Naploes-Springer *et al* in a qualitative study also found that most women were satisfied with their treatment decisions.⁶¹

3.4.3B Difficulties experienced in treatment decision-making

Three qualitative studies^{49,60,62} highlighted some of the difficulties women with DCIS experienced in treatment decision-making. The difficulties women experienced included confusion about being offered treatments used to treat invasive breast cancer, especially a mastectomy, when they did not have ‘real’ breast cancer (“*It felt like they were using a sledgehammer to crack a nut.*”);^{49,60,62} whether treatment was really necessary given the uncertainty about whether DCIS would develop into invasive breast cancer;^{49,60,62} inadequate information about DCIS;^{49,60} inadequate information about treatment options, including knowing why certain options were not indicated;⁶¹ a lack of a specific treatment recommendation;⁶¹ feeling ‘rushed’ into treatment⁶² and, in contrast, feeling that there was too much time between diagnosis and treatment.⁶¹

3.4.3C Factors influencing treatment decisions

One qualitative study⁶¹ explored the factors influencing treatment decisions. Napoles-Springer *et al* found that the following factors influenced treatment decisions (in order of importance): firstly, having surgery to “get rid of it”; secondly, family history of cancer, cancer experiences of acquaintances, and fear of side effects; and thirdly, fear of recurrence and physicians’ recommendations.⁶¹

3.4.3D Perceived level of involvement in treatment decision-making

None of the quantitative studies assessed women’s perceived level of involvement in treatment decision-making. Napoles-Springer *et al* in a qualitative study found that most women felt they had made treatment decisions with their physicians.⁶¹

See *Table 1.7 (Page 78)* for the key findings related to the theme of *Treatment decision-making*.

3.4.4 Psychological morbidity

3.4.4A Confusion relating to the diagnosis

Confusion is distinct from knowledge and has been described as one of the dimensions of emotional distress.^{70,71} None of the quantitative studies assessed confusion relating to the diagnosis. Three qualitative studies^{49,60,62} found that the central confusion for women with DCIS was whether they had cancer that could metastasize and result in death (“*Well have I got cancer or haven’t I.*”). Women’s confusion was compounded by the different terms such as ‘very early breast cancer’, ‘pre-cancer’, ‘carcinoma in situ’, and ‘non-invasive breast cancer’ used by health professionals and in written information (including information from the Internet) to describe their diagnosis, and by the recommendation of treatments such as a mastectomy.^{49,60,62}

3.4.4B Psychological distress and well-being

Two large longitudinal cohort studies^{51,52} and four smaller cross-sectional studies⁵⁵⁻⁵⁸ assessed psychological distress and well-being in women with DCIS, as measured by the SF-36,^{51,52,55} HADS,⁵¹ WHO-5,⁵⁵ CES-D,⁵⁷ and non-standardised measures.^{56,58} Five qualitative studies^{49,60-64} explored psychological distress and well-being in women with DCIS.

Two longitudinal cohort studies^{52,51} and one cross-sectional study⁵⁵ assessed mental health using the SF-36 in women diagnosed with DCIS with mixed results. Nekhlyudov *et al* in a longitudinal cohort study found that women with DCIS experienced small short term (within six months of the diagnosis) decline in their mental health but had good mental health in the long term.⁵² ‘Mental health’ is a domain of the SF-36 which measures the

degree of psychological distress, that is, anxiety, depression, and loss of behavioural or emotional control; and psychological well-being.⁷² The study assessed mental health in a cohort of registered nurses who may have greater access to information and support about their diagnosis and therefore may have better mental health than women with DCIS from the general population. Van Gestal *et al* in a cross-sectional study also found good mental health in the long term among women with DCIS, as measured by the SF-36.⁵⁵ Van Gestal *et al* found that the mean mental health score of women with DCIS was not significantly different from those in the general Dutch female population (by age using normative data) at 2-3 years after treatment. The results by Nekhlyudov *et al* and Van Gestal *et al* suggest that women with DCIS have good mental health particularly in the long-term.

Alternatively, the results may be due to the response shift (changes in the meaning of one's self-evaluation resulting from changes in internal standards, values, or conceptualisation).⁷³

In contrast, Partridge *et al* in a longitudinal cohort study found that the mental health of women with DCIS *decreased* over time with the mean mental health score of the SF-36 being significantly lower at 18 months follow-up compared to enrolment (within six months of the diagnosis).⁵¹ The mean mental health score at 18 months follow-up was also found to be below population normal scores by age.

However, Partridge *et al* also assessed anxiety and depression using the HADS and found that anxiety decreased significantly from 10% of women at enrolment (within six months of the diagnosis) to 6% (at eighteen months follow-up), and remained at 2% for depression.⁵¹

Two cross-sectional studies compared the psychological morbidity in women with DCIS and invasive breast cancer using the SF-36,⁵⁵ the WHO-5,⁵⁵ and a non-standardised measure⁵⁶ with mixed results. Rakovitch *et al* compared the psychological morbidity in women with DCIS and invasive breast cancer in the short term and found that women with DCIS had similar levels of psychological morbidity to women with invasive breast cancer.⁵⁶ The study surveyed women shortly after surgery and found that 40% of DCIS women reported that they 'often' or 'very often' had trouble sleeping, 41% reported unhappiness/depression 'often' or 'very often', and 56% reported nervousness/anxiety, using a non-standardised measure. However, the results of the study are limited by the lack

of comparison data for the general population and the use of a non-standardised measure. Van Gestel *et al* compared the psychological morbidity in women with DCIS and invasive breast cancer in the long term and found that women with DCIS had significantly better mental health than women with invasive breast cancer at 2-3 years after treatment, as measured by the SF-36. However, Van Gestel *et al* also found that women with DCIS had similar levels of psychological morbidity to women with invasive breast cancer at 2-3 years after treatment, as measured by the WHO-5.⁵⁵ Of note, the mean scores on the WHO-5 and the SF-36 were not significantly different from those in the general Dutch female population by age using normative data. The results suggest that women with DCIS, and women with invasive breast cancer, have good psychological health particularly in the long-term. Alternatively, the results may be due to the response shift as discussed above.

Two cross-sectional studies^{57,58} assessed psychological morbidity among DCIS women (without a comparison group of women with invasive breast cancer) in the long term. Bluman *et al* found that 15% of women were depressed when surveyed 1.9 years (mean) after the diagnosis using the Centre for Epidemiologic Studies Depression Scale (CES-D).⁵⁷ A study of depression in community samples using the CES-D found that 21% of people were depressed.⁷⁴ The results suggest that women with DCIS have good psychological health in the long term. Amichetti *et al* surveyed women with DCIS 4.5 years (median) after treatment using a non-standardised scale and found that 46% of women felt they were tense, 48% nervous, 29% lonely, 59% anxious, and 41% depressed.⁵⁸ However, the results of the study are limited by a lack of comparison data from the general population, the use of a non-standardised measure, and the long time since diagnosis of the survey.

Three qualitative studies^{49,60,62} found that many women with DCIS described the experience of being diagnosed and treated for DCIS as a stressful and difficult time. Kennedy *et al* also found that some women who thought that they did not have 'real' breast cancer felt guilty about reacting emotionally to their diagnosis.⁶⁰

3.4.4C Cancer-specific worry

One longitudinal cohort study,⁵¹ one cross-sectional study,⁵⁷ and one qualitative study assessed cancer-specific worry in women with DCIS.⁶⁰ ‘Cancer-specific worry’ has been shown to be distinct from risk perception,^{75,76} and anxiety and depression.^{77,78} However, there are divergent definitions and measurement strategies for cancer-specific worry in the literature.⁷⁵

Partridge *et al* in a longitudinal cohort study⁵¹ and Bluman *et al* in a cross-sectional study⁵⁷ assessed cancer-specific worry in terms of the level of ‘intrusive or avoidant thoughts’ in response to the diagnosis as measured by the RIES. The RIES does not measure the content of the ‘intrusive or avoidant thoughts’. Partridge *et al* found that women with DCIS had a substantial degree of cancer-specific worry at enrolment (within 6 months of the diagnosis) that statistically significantly improved over the next 9 to 18 months. Bluman *et al* surveyed women with DCIS 1.9 years (mean) after the diagnosis and found a low level of cancer-specific worry as measured by the RIES. The results by Partridge *et al* and Bluman *et al* suggest that women with DCIS experience a high level of cancer-specific worry (measured as ‘intrusive or avoidant thoughts’ in response to the diagnosis) mainly in the short term.

However, Bluman *et al*⁵⁷ also measured cancer-specific worry in women with DCIS in terms of the level of ‘worry about getting breast cancer’ using The Breast Cancer Worry Scale (BCWS) and found that 42% of women were either ‘moderately’ or ‘very’ concerned about ‘getting breast cancer’ when surveyed 1.9 years (mean) after their diagnosis. The study would have benefited by comparison data from women with invasive breast cancer. Kennedy *et al* in a qualitative study found that some women with DCIS worried about breast cancer recurrence even years after treatment.⁶⁰ The results by Bluman *et al* and Kennedy *et al* suggest that women with DCIS experience a high level of cancer-specific worry (measured as ‘worry about getting breast cancer’) in the long term.

3.4.4D *Impact of asymptomatic disease*

Most women with DCIS are diagnosed through screening mammography and are asymptomatic at the time of diagnosis. Three qualitative studies highlighted that ‘not feeling ill’, that is, being asymptomatic at the time of diagnosis compounded women’s feeling of shock and distress when diagnosed with DCIS.^{49,60,64} However, Prinjha *et al* found that some women with DCIS were reassured by their lack of symptoms and thought that this meant that the “problem” was “a small one”.⁶²

3.4.4E *Communication and support from clinicians*

One longitudinal cohort study⁵¹ and four qualitative studies^{49,60,61,63} explored women’s satisfaction with the communication and support from their primary clinician. Partridge *et al* in a longitudinal cohort study found that 83% of women with DCIS thought that their surgeon was the most influential in their care, 10% a medical oncologist, 5% a radiation oncologist, and 2% another sub specialist.⁵¹ Almost all women thought that the communication with their most influential clinician was ‘good’, ‘very good’ or ‘excellent’ and most women were satisfied with the care they received for their DCIS. However, the results of the study were limited by the lack of assessment of women’s satisfaction with various aspects of communication or care and the use of non-standardised measures.

Three qualitative studies^{49,61,63} also found that most women with DCIS were satisfied with the emotional support and care they received from their primary clinician. De Morgan *et al* found that most women with DCIS were very satisfied with the emotional support they received from their primary clinician.⁴⁹ Brown *et al* found that the surgeon had a significant role in reducing anxiety and reassuring women of their good prognosis and fostering a sense of trust in the information given.⁶³ Trust in the primary clinician was found to be related to the willingness of the doctor to answer women’s questions. Naploes-Springer *et al* found that most women with DCIS were satisfied with their care and that satisfaction was associated with adequate information, expediency of telling women their diagnosis and

arranging treatment, and physician's sensitivity to their emotional needs, including feeling that their doctor was friendly and cared about them.⁶¹

However, Kennedy *et al* in a qualitative study found that some women with DCIS perceived that health professionals minimised the emotional impact of the diagnosis of DCIS (“*A lot of us are told when we are diagnosed with DCIS that we are lucky. We're very fortunate...when you are feeling absolutely depressed...* ”⁶⁰). Although women were partly reassured by a better prognosis, women felt they had to cope with the uncertainties involved in their diagnosis and had to undergo treatments similar to women with invasive breast cancer and therefore needed the same level of emotional support that health professionals provided to women with invasive breast cancer.

3.4.4F Support groups

Two qualitative studies^{49,60} explored women's satisfaction with the support they received from support groups. Kennedy *et al* and De Morgan *et al* found that some women with DCIS benefited from support groups for women with invasive breast cancer. However, some women wanted support groups specifically for women with DCIS, including Internet support groups, to address their particular issues and concerns and “reduce the isolation of the diagnosis.”

See *Table 1.7 (Page 78)* for the key findings related to the theme of ***Psychological morbidity***.

3.4.5 Sexuality

The review did not find any data about women's perceptions of the impact of the diagnosis and treatment of DCIS on their sexuality and body image in the short term (within six months of the diagnosis). Three cross-sectional studies^{55,57,58} and one qualitative study⁶⁰ explored the impact of the diagnosis and treatment on women's sexuality and body image in the long term with mixed results.

Bluman *et al* in a cross-sectional study found that half of women with DCIS who considered themselves sexually active reported decreased interest in sex and decreased sexuality activity since their diagnosis, 33% reported feelings of sexual unattractiveness, and 16% reported decreased feelings of sexual acceptance by their partners when surveyed 1.9 years (mean) after their diagnosis.⁵⁷ Kennedy *et al* in a qualitative study found that some women with DCIS were not satisfied with their body image after treatment.⁶⁰ However, Amichetti *et al* in a cross-sectional study found that only 10% of women who were sexually active thought the diagnosis and treatment had negative effects on their sexuality when surveyed 4.5 years (median) after their treatment.⁵⁸ The results of the study were limited by the long time since diagnosis of the survey.

Van Gestal *et al* in a cross-sectional study found that women with DCIS perceived that the disease and treatment had a *positive* impact on their sex life, unlike women with invasive breast cancer who perceived that the disease and treatment had a negative impact on their sex life, when surveyed 2-3 years after treatment.⁵⁵ This is an example of benefit finding or post-traumatic growth.⁷⁹ Treatment factors may explain some of the differences between the two groups, with women with DCIS in the study being significantly less likely to have hormonal therapy than women with invasive breast cancer.

See *Table 1.7 (Page 78)* for the key findings related to the theme of ***Sexuality***.

3.4.6 Relationships, social support and functioning

Two large longitudinal cohort studies,^{52,51} three smaller cross-sectional studies,^{55,56,58} and one qualitative study⁶⁰ explored the impact of the disease and treatment of DCIS on women's relationships; women's social support; and women's social functioning.

3.4.6A *Interpersonal relationships*

Two cross-sectional studies compared the impact of the disease and treatment of DCIS and invasive breast cancer on women's relationships.^{55,56} Rakovitch *et al* assessed the short term impact (women surveyed shortly after surgery) of the disease and treatment on women's relationships.⁵⁶ The study found that women with DCIS and invasive breast cancer perceived a similar negative impact in terms of withdrawing from others and strained interpersonal relationships. However, the percentage of women who experienced a negative impact on their interpersonal relationships was relatively low ($\leq 15\%$). Van Gestal *et al* assessed the long term impact (women surveyed 2-3 years after treatment) of the disease and treatment on women's relationships.⁵⁵ The study found that women with DCIS and women with invasive breast cancer perceived that the disease and treatment had a similar *positive* impact on their family relations, relatives, spouse, friends and acquaintances. This is another example of benefit finding or post-traumatic growth.⁷⁹ The results of the studies by Rakovitch *et al* and Van Gestal *et al* suggest that some women with DCIS experience negative consequences of the diagnosis and treatment on their relationships in the short term, and that some women with DCIS experience positive long term consequences on their relationships. The results may also be influenced by the differences in the measures used in the studies, with the measure used in the study by Van Gestal *et al* including positive and negative response options and the measure used in the study by Rakovitch *et al* including only negative and neutral response options.

3.4.6B *Social support*

One large longitudinal study⁵¹ and one qualitative study⁶⁰ explored social support in women with DCIS. Partridge *et al* in a longitudinal study found that women with DCIS had a high degree of social support at enrolment (within six months of diagnosis) as measured by the MOS Social Support Scale (MOS-SS). Although this study used a longitudinal design the authors did not report changes in social support over time.⁵¹ Kennedy *et al* in a qualitative study found that the support from family helped women most to cope with their diagnosis and treatment.⁶⁰ The study also found that for some women, who thought they

did not have the ‘real’ breast cancer, this support was complicated by others misperceiving their diagnosis as invasive breast cancer.

3.4.6C *Social functioning*

Two large longitudinal cohort studies^{52,51} and two smaller cross-sectional studies^{55,58} assessed social functioning in women with DCIS as measured by the SF-36^{51,52,55} and a non-standardised scale.⁵⁸ ‘Social functioning’ measures the degree to which an individual’s emotional or physical problems disrupt his/her normal social activities.⁷² Nekhlyudov *et al* in a longitudinal cohort study found that women with DCIS experience small short term (within six months of the diagnosis) decline in their social functioning but had good social functioning in the long term, as measured by the SF-36.⁵² However, Partridge *et al* in a longitudinal cohort study found no significant decrease in social functioning at enrolment (within six months of diagnosis) compared to pre-diagnosis, as measured by the SF-36.⁵¹ The reliability of the pre-diagnosis data is limited as it was measured by women’s recall at enrolment. The study was also unable to measure long-term social functioning due to an omission of the item at 18 months follow-up.

Van Gestal *et al* in a cross-sectional study found that women with DCIS had similar social functioning to women with invasive breast cancer as measured by the SF-36 at 2-3 years after treatment.⁵⁵ However, the mean score was not significantly different from scores in the general Dutch female population by age using norm data. The results suggest good long term social functioning in women with DCIS. Amichetti *et al* in a cross-sectional study also found good long term social functioning in women with DCIS.⁵⁸ The study found that only 8% of women felt the treatment had a negative effect on their social life when surveyed a median 4.5 years after treatment using a non-standardised scale.

See Table 1.7 (Page 78) for the key findings related to the theme of ***Relationships, social support and functioning***.

3.4.7 *Physical health*

3.4.7A *Physical health and functioning*

Two large longitudinal cohort studies^{51,52} and two smaller cross-sectional studies^{55,58} assessed physical health and functioning in women with DCIS as measured by the SF-36^{51,52,55} and non-standardised scales.^{55,58} One qualitative study⁶⁰ explored the physical health of women with DCIS.

Nekhlyudov *et al* in a longitudinal cohort study found that women with DCIS experience small short term (within six months of the diagnosis) decline in their physical health and functioning such as reduced vitality and limitations in role functioning due to physical problems but had good physical health and functioning in the long term, as measured by the SF-36.⁵² ‘Vitality’ measures energy level and fatigue, and ‘role functioning due to physical problems’ measures the extent of problems with work or daily activities as a result of physical health.⁷²

Partridge *et al* in a longitudinal cohort study did not find significant decline in physical health and functioning in women with DCIS in the short term (within 6 months of diagnosis) or the long term (at 18 months follow-up), as measured by the SF-36.⁵¹ The study found that physical health and functioning including ‘physical functioning’ (magnitude of limitation in performing all physical activities), ‘role limitations due to physical health problems’ (defined above), and ‘bodily pain’ (the magnitude of bodily pain and the extent of interference in normal activities because of pain) were only slightly lower at enrolment (within six months of diagnosis) than before diagnosis. However, the reliability of the pre-diagnosis data is limited as it was measured by women’s recall at enrolment. Partridge *et al* did not find any decline in physical functioning and health in women with DCIS at 18 months follow-up, apart from ‘general health perceptions’ (perceptions of personal health ranging from ‘getting sick easily’ to ‘excellent health’) and vitality (defined above), compared to enrolment (within 6 months of diagnosis). The mean scores in women with DCIS at 18 months follow-up for physical health and functioning,

apart from vitality, compared well with population normal scores by age. The results suggest good short term and long term physical health and functioning in women with DCIS.

Van Gestel *et al* in a cross-sectional study found that in the long term (2-3 years after treatment) women with DCIS had significantly less 'bodily pain' (defined above) than women with invasive breast cancer, as measured by the SF-36.⁵⁵ However, women with DCIS and invasive breast cancer had significantly *better* scores on the subscale bodily pain compared to the general Dutch female population by age using norm data. The results may be due to the response shift (changes in the meaning of one's self-evaluation resulting from changes in internal standards, values, or conceptualisation).⁷³

Van Gestel *et al* also found that women with DCIS perceived that the disease and treatment had a *positive* impact on their physical health compared to women with invasive breast cancer who perceived that the disease and treatment had a negative impact on their physical health, when surveyed 2-3 years after treatment using a non-standardised measure. This is another example of benefit finding or post-traumatic growth.⁷⁹ Treatment factors may explain some of the differences between the two groups, with women with DCIS in the study being significantly less likely to have radiotherapy, sentinel node biopsy or hormonal therapy than women with invasive breast cancer. Amichetti *et al* in a cross-sectional study also found good long-term physical health in women with DCIS, using a non-standardised scale.⁵⁸ Most women reported that they felt physically well and energetic when surveyed median 4.5 years after treatment.

Kennedy *et al* in a qualitative study found that some women with DCIS, particularly women who had a mastectomy, experienced difficulties with prostheses, stiffness, pain and discomfort.⁶⁰

3.4.7B Physical activity and weight gain

Two large longitudinal cohort studies assessed physical activity in women following a diagnosis of DCIS.^{50,54} Ligibel *et al* found that a large proportion of women with DCIS was inactive at enrolment (within 3 months of surgery) and remained so 18 months later, as measured by a non-standardised measure. The study also found that women with DCIS who were more anxious, and women who had a mastectomy, were more likely to decrease their physical activity. The study did not explore whether physical and/or psychological factors affected physical activity in women who had a mastectomy. In addition, the study did not control for the potential bias created by only some women having completed radiotherapy at the time of the initial assessment. Some women in the study may have already changed their physical activity level before enrolment onto the study.

Irwin *et al*⁵⁴ found that women with DCIS were significantly less active during their first year after diagnosis (4-12 months after the diagnosis) than they were one year before the diagnosis, as measured by a standardised scale. Approximately half of women with DCIS, and approximately half of women with invasive breast cancer, decreased their total physical activity from pre-diagnosis to the first year of diagnosis. However, the pre-diagnosis data for the year prior to diagnosis was obtained from women's recall at the post-diagnosis assessment and are subject to recall bias. The study also did not control for the potential bias created by only some women having completed treatment at the time of the assessment. Some women in the study may have already changed their physical activity level before enrolment onto the study.

Irwin *et al*⁵³ in a longitudinal study that included the same cohort of women as Irwin *et al* previous study⁵⁴ found that women with DCIS increased their weight and body fat from the first year of diagnosis (4-12 months after the diagnosis) to their third year of diagnosis (2 years after the initial assessment). However, greater weight and body fat gains were found in women with invasive breast cancer (mean 1.7 kg weight gain) compared to women with DCIS (mean 0.9 kg weight gain). Among women with DCIS and invasive breast cancer, greater increases in weight were observed in women who were younger age,

postmenopausal, and who decreased their physical activity. The study did not control for the potential bias created by only some women having completed treatment at the time of the initial assessment. Some women in the study may have already experienced changes in weight or body fat before enrolment onto the study.

See Table 1.7 (Page 78) for the key findings related to the theme of ***Physical health***.

3.4.8 Benefits of the diagnosis

The phenomenon of benefiting from an experience that is also associated with harms is referred to as posttraumatic growth or benefit finding.⁷⁹ One cross-sectional study⁵⁵ and one qualitative study⁶⁰ explored the positive impact of a diagnosis of DCIS. Van Gestal *et al* found that the diagnosis had a *positive* effect on most life-domains for women with DCIS, and women with invasive breast cancer, in the long term (2-3 years after treatment) using a non-standardised measure.⁵⁵ The most positive influence of the disease for women with DCIS was seen on women's outlook on life, self-expression/self-improvement, diet, and family relations. This study was the only observational study included in the review which used a Health Related Quality of Life measure that included positive responses. All other measures used by the other studies in the review included negative and neutral responses and so were unable to explore the positive impact of a diagnosis of DCIS. Kennedy *et al* in a qualitative study explored the benefits of the diagnosis of DCIS and found that some women with DCIS felt that the diagnosis had increased their empathy and personal strength.⁶⁰

See Table 1.7 (Page 78) for the key findings related to the theme of ***Benefits of the diagnosis***.

3.4.9 Experiences of women with DCIS from culturally and linguistically diverse (CALD) backgrounds

Two qualitative studies explored the experience of Latina American women⁶¹ and Chinese Canadian women⁵⁹ diagnosed with DCIS.

3.4.9A Latina American women

Naploes Springer *et al* compared the experiences of Latina women and non-Latina white US women diagnosed with DCIS and found that Latina women had poorer knowledge about DCIS and reported more psychological distress related to their diagnosis than non-Latina white women.⁶¹ Most Latina women could not clearly describe their diagnosis, were more likely to be confused about whether they had cancer or not, and were more likely to view their diagnosis as life-threatening compared to most non-Latina white women who were aware that they had a non-invasive breast cancer that could not spread and that they had a good chance of survival. Latina women also had poorer knowledge about their treatments such as surgery, radiotherapy and Tamoxifen than non-Latina white women.

Latina women and non-Latina women were equally likely to want to know all the treatment options, including why certain options were not indicated. Latina women and non-Latina women also reported similar factors that influenced their treatment decisions such as ‘getting rid of it’, family history, cancer experiences of acquaintances, fear of side effects and recurrence, and physicians’ recommendations. In addition, Latina women and non-Latina women reported similar factors that were important to them in feeling satisfied with their care such as receiving adequate information, expediency of the diagnosis and treatment, and sensitivity to women’s emotional needs.

3.4.9B Chinese Canadian women

Wong *et al* explored the experiences of treatment decision-making in Chinese Canadian women with DCIS and found that women’s treatment decisions reflected a lack of

understanding about DCIS and a preference for mastectomy.⁵⁹ Most women were presented with the options of lumpectomy and mastectomy. However, half of the women who were given the option of lumpectomy chose a mastectomy to “rid themselves of breast cancer forever”.

Most women in the study described their diagnosis as ‘breast cancer’ and only a minority of women understood that their type of breast cancer was confined to the milk ducts in the breast. Fear of recurrence, suffering and premature death were predominant amongst the women in the study. Women’s treatment decisions were influenced by significant others such as their husbands, Chinese-speaking family physicians, friends and family members, especially people with health care backgrounds. Women sought additional information from the Chinese Cancer Hotline, other women with breast cancer, and library books to help them understand their diagnosis and the treatment options. Women in the study reported that they needed more information support in Chinese.

The study also found that many Chinese Canadian women felt that they had benefited from the diagnosis of DCIS in that it had ‘restored a sense of satisfaction with their lives’, motivated them to ‘live in the present’ or to engage in healthy lifestyles.

See *Table 1.7 (Page 78)* for the key findings related to the theme of ***Experiences of women with DCIS from culturally and linguistically diverse (CALD) backgrounds.***

Table 1.7: Key findings from the review

Key LC longitudinal cohort study CS cross sectional study QS qualitative study

Key findings		Type of study		
		LC	CS	QS
1	Knowledge			
A	<i>Description of the diagnosis</i>			
i	The terms women with DCIS used to describe their diagnosis varied greatly and included early breast cancer, a 'contained' non-invasive breast cancer, not a 'real' breast cancer, a pre-cancer, and a benign condition.			49 60- 64
B	<i>DCIS-related risk perceptions</i>			
i	Many women with DCIS have been found to overestimate their risk of local recurrence, metastases and dying from breast cancer.	51	55- 57	49 60
ii	Inaccurate risk perceptions among women with DCIS did not change over time.	51		
iii	Inaccurate risk perceptions among women with DCIS were associated with higher levels of anxiety and cancer-specific worry.	51		49, 60
C	<i>Knowledge about the natural history of DCIS</i>			
i	Only some women with DCIS were aware that not all women would develop invasive breast cancer if untreated.			49 60 62
D	<i>Knowledge of DCIS prior to the diagnosis</i>			
i	Most women with DCIS had no prior knowledge about DCIS before their diagnosis and that little information about DCIS was available at mammographic screening.			60 62
2	Information needs			
A	<i>Satisfaction with information</i>			
i	Many women with DCIS were dissatisfied with the amount of written and verbal information they received specifically about DCIS.			49 60- 63

Key findings		Type of study		
		LC	CS	QS
ii	Satisfaction with information was related to women with DCIS feeling that they had received thorough explanations from their doctor about aspects of their care and that they could ask their doctor questions.			49 61 63
iii	90% of women with DCIS were 'mostly' or 'very' satisfied with the 'information from doctors' when surveyed 1.9 years (mean) after their diagnosis using a non-standardised measure. Approximately one third of women were 'not satisfied' or only 'somewhat satisfied' with 'information related to future health problems'.		57	
iv	79% of women with DCIS considered the 'information about the disease' sufficient, 75% considered the 'information about surgery' sufficient, and 79% considered the 'information about radiotherapy' sufficient when surveyed 4.5 years (median) after their treatment using a non-standardised measure.		58	
v	Women with DCIS wanted more information about the following: what DCIS is and whether it is cancer or not; the risk of DCIS developing into invasive breast cancer or 'progressing' including the uncertainties; whether surgery is really necessary when DCIS may not develop into invasive breast cancer; the pathological findings after surgery for example, margins, size; whether 'cancer' would recur; whether 'they'd got it all'; the risk of a daughter developing breast cancer; physical treatment issues; and the roles of the different specialists.			49 60- 63
B	<i>Sources of information</i>			
i	Many women with DCIS considered the most important source of information was their clinician.			49 61 63
ii	Many women with DCIS sought information from sources other than their treatment team, such as the Internet, journals, books, and other health professionals.			49 60 62 63
C	<i>Methods to increase women's understanding and recall</i>			
i	Methods suggested by women with DCIS to increase their understanding and recall about DCIS include: providing advice about appropriate websites, books or articles for more information about DCIS; audio-taping consultations; using diagrams and writing key messages during consultations; and encouraging the woman to bring a friend into the consultations.			60 63

Key findings		Type of study		
		LC	CS	QS
D	<i>Information at mammographic screening</i>			
i	Many women want more information about DCIS during mammographic screening.			60 62
ii	Half of women felt the omission of information about DCIS at mammographic screening prevented them from making fully informed decisions about whether to attend mammographic screening.			62
3	Treatment decision-making			
A	<i>Satisfaction with aspects of treatment decision-making</i>			
i	Most women with DCIS were satisfied with their ‘choice of treatment’ and ‘the ability to make treatment decisions’.		57	61
B	<i>Difficulties experienced in treatment decision-making</i>			
i	The difficulties women with DCIS experienced in treatment decision-making included: confusion about being offered treatments used to treat invasive breast cancer, especially a mastectomy, when they did not have ‘real’ breast cancer; whether treatment was really necessary given the uncertainty about whether DCIS would develop into invasive breast cancer; inadequate information about DCIS; inadequate information about treatment options, including knowing why certain options were not indicated; a lack of a specific treatment recommendation; feeling “rushed” into treatment and, in contrast, feeling that there was too much time between diagnosis and treatment.			49 60 62
C	<i>Factors influencing treatment decisions</i>			
i	Factors influencing treatment decisions for women with DCIS included (in order of importance) firstly, having surgery to ‘get rid of it’; secondly, family history, cancer experiences of acquaintances, and fear of side effects; and thirdly, fear of recurrence and physicians’ recommendations.			61
D	<i>Perceived level of involvement in treatment decision-making</i>			
i	Most women with DCIS felt that they had made the treatment decisions with their physicians.			61

Key findings		Type of study		
		LC	CS	QS
4	Psychological morbidity			
A	<i>Confusion relating to the diagnosis</i>			
i	The central confusion for women with DCIS was whether they had cancer that could metastasize and result in death.			49 60 62
ii	Women's confusion about their diagnosis was compounded by the different terms used by various health professionals to describe their diagnosis. Women's confusion was compounded by the different terms such as 'very early breast cancer', 'pre-cancer', 'carcinoma in situ', and 'non-invasive breast cancer' used by health professionals and in written information (including information from the Internet) to describe their diagnosis, and by the recommendation of treatments such as a mastectomy.			49 60 62
B	<i>Psychological distress and well-being</i>			
i	Women with DCIS experienced small short term (within six months of the diagnosis) decline in their mental health but had good mental health in the long term, as measured by the SF-36.	52		
ii	The mean mental health score (SF-36) of women with DCIS was not significantly different from those in the general female population (by age using norm data) at 2-3 years after treatment.		55	
iii	The mental health of women with DCIS decreased over time with the mean mental health score of the SF-36 being significantly lower at 18 months follow-up compared to enrolment (within six months of the diagnosis). ⁵¹ The mean mental health score at 18 months follow-up was also found to be below population normal scores by age.	51		
iv	Anxiety in women with DCIS decreased significantly from 10% of women at enrolment (within six months of their diagnosis) to 6% (at 18 months follow-up), and remained at 2% for depression, as measured by the HADS.	51		
v	15% of women with DCIS were depressed when surveyed 1.9 years (mean) after their diagnosis, as measured by the CES-D.		57	

Key findings		Type of study		
		LC	CS	QS
vi	Women with DCIS had similar levels of psychological morbidity to women with invasive breast cancer at 2-3 years after treatment, as measured by the WHO-5. ⁵⁵ However, the mean scores on the WHO-5 were not significantly different from those in the general female population by age using norm data.		55	
vii	Women with DCIS had significantly better mental health than women with invasive breast cancer at 2-3 years after treatment, as measured by the SF-36. However, the mean scores on the SF-36 were not significantly different from those in the general female population by age using norm data.		55	
viii	Women with DCIS had similar levels of psychological morbidity to women with invasive breast cancer in the short term (after surgery), as measured by a non-standardised measure.		56	
ix	Many women with DCIS described the experience of being diagnosed and treated for DCIS as a stressful and difficult time.			49 60 62
C	<i>Cancer-specific worry</i>			
i	Women with DCIS had a substantial degree of cancer-specific worry at enrolment (within six months of the diagnosis) that statistically significantly improved over the next 9 to 18 months, as measured by the RIES.	51		
ii	Women with DCIS had a low level of cancer-specific worry when surveyed 1.9 years (mean) after their diagnosis, as measured by the RIES.		57	
iii	42% of women with DCIS were either 'moderately' or 'very' concerned about 'getting breast cancer' when surveyed 1.9 years (mean) after their diagnosis, as measured by the Breast Cancer Worry Scale.		57	
iv	Some women with DCIS worried about breast cancer recurrence even years after treatment.			60
D	<i>Impact of asymptomatic disease</i>			
i	Most women with DCIS are diagnosed through screening mammography and are asymptomatic at the time of diagnosis. 'Not feeling ill' compounded women's feeling of shock and distress when diagnosed with DCIS.			49 60 62

Key findings		Type of study		
		LC	CS	QS
ii	Some women with DCIS were reassured by their lack of symptoms and thought that this meant that the ‘problem’ was ‘a small one’.			62
E	<i>Communication and support from clinicians</i>			
i	83% of women with DCIS thought that their surgeon was the most influential in their care, 10% a medical oncologist, 5% a radiation oncologist, and 2% another sub specialist.	51		
ii	Almost all women with DCIS thought that the communication with their most influential clinician was ‘good’, ‘very good’ or ‘excellent’ and most women were satisfied with the care they received for their DCIS, as measured by non-standardised measures.	51		
iii	Most women with DCIS were very satisfied with the emotional support they received from their primary clinician such as their surgeon or oncologist.			49
iv	Most women with DCIS were satisfied with their care and satisfaction was associated with adequate information, expediency of telling women their diagnosis and arranging treatment, and physician’s sensitivity to their emotional needs, including feeling that their doctor was friendly and cared about them.			61
v	The surgeon had a significant role in reducing anxiety and reassuring women with DCIS of their good prognosis and fostering a sense of trust in the information given. Trust in the primary clinician was found to be related to the willingness of their doctor to answer questions.			63
vi	Some women with DCIS perceived that health professionals minimised the emotional impact of the diagnosis of DCIS. Although women were partly reassured by a better prognosis, women felt they had to cope with the uncertainties involved in their diagnosis and had to undergo treatments similar to women with invasive breast cancer and therefore needed the same level of emotional support that health professionals provided to women with invasive breast cancer.			60
H	<i>Support groups</i>			
i	Some women with DCIS wanted support groups specifically for women with DCIS, including Internet support groups, to address their particular issues and concerns.			49 60

Key findings		Type of study		
		LC	CS	QS
5	Sexuality			
i	Women with DCIS perceived that the disease and treatment had a positive impact on their sex life unlike women with invasive breast cancer who perceived that the disease and treatment had a negative impact on their sex life, when surveyed 2-3 years after treatment.		55	
ii	Half of women with DCIS who considered themselves sexually active reported decreased interest in sex and decreased sexuality activity since their diagnosis, 33% reported feelings of sexual unattractiveness, and 16% reported decreased feelings of sexual acceptance by their partners when surveyed 1.9 years (mean) after their diagnosis.		57	
iii	10% of women with DCIS who were sexually active thought the diagnosis and treatment had negative effects on their sexuality, and 16% of women reported that they had worsened body image, when surveyed 4.5 years (median) after their treatment.		58	
6	Relationships, social support and functioning			
A	<i>Interpersonal relationships</i>			
i	Women with DCIS and women with invasive breast cancer perceived that the disease and treatment had a similar positive impact on their family relations, relatives, spouse, friends and acquaintances, when surveyed 2-3 years after treatment.		55	
ii	Women with DCIS and invasive breast cancer perceived a similar negative impact in terms of withdrawing from others and strained interpersonal relationships, when surveyed shortly after surgery using a non-standardised measure. However, the percentage of women who experienced a negative impact on their interpersonal relationships was relatively low ($\leq 15\%$).		56	
B	<i>Social support</i>			
i	Women with DCIS had a high degree of social support at enrolment (within six months of diagnosis) as measured by the MOS Social Support Scale (MOS-SS).	51		
ii	The support from family helped women with DCIS most to cope with their diagnosis and treatment.			60

Key findings		Type of study		
		LC	CS	QS
C	<i>Social functioning</i>			
i	Women with DCIS experience small short term (within six months of the diagnosis) decline in their social functioning but had good social functioning in the long term, as measured by the SF-36.	52		
ii	Women with DCIS had similar social functioning to women with invasive breast cancer, when surveyed 2-3 years after treatment using the SF-36. However, the mean score was not significantly different from those in the general female population by age using norm data.		55	
iii	Only 8% of women with DCIS felt the treatment had a bad effect on their social life when surveyed a median 4.5 years after treatment, using a non-standardised scale		58	
7	Physical health			
A	<i>Physical health and functioning</i>			
i	Women with DCIS experience small short term (within six months of the diagnosis) decline in their physical health and functioning such as reduced vitality and limitations in role functioning due to physical problems but had good physical health and functioning in the long term, as measured by the SF-36.	52		
ii	There was no significant decline in physical health and functioning in women with DCIS in the short term (within six months of diagnosis) or the long term (at 18 months follow-up), as measured by the SF-36. The mean scores in women with DCIS at 18 months follow-up for physical health and functioning, apart from vitality, compared well with population normal scores by age.	51		
iii	Women with DCIS perceived that the disease and treatment had a positive impact on their physical health compared to women with invasive breast cancer who perceived that the disease and treatment had a negative impact on their physical health, when surveyed at 2-3 years after treatment using a non-standardised measure.		55	

Key findings		Type of study		
		LC	CS	QS
iv	Women with DCIS had significantly less bodily pain than women with invasive breast cancer, when surveyed at 2-3 years after treatment using the SF-36. However, women with DCIS and invasive breast cancer had significantly better scores on the subscale bodily pain compared to the general female population by age using norm data.		55	
v	Most women with DCIS reported that they felt physically well and energetic when surveyed median 4.5 years after treatment using a non-standardised scale.		58	
vi	Some women with DCIS, particularly women who had a mastectomy, experienced difficulties with prostheses, stiffness, pain and discomfort.			60
B	<i>Physical activity and weight gain</i>			
i	A substantial proportion of women with DCIS was inactive at enrolment (within three months of surgery) and remained so 18 months later, as measured by a non-standardised scale.	50		
ii	Women with DCIS who had a mastectomy, and women who were more anxious were found to be more likely to decrease their physical activity.	50		
iii	Women with DCIS were significantly less active during their first year after diagnosis (4-12 months after the diagnosis) than they were one year before the diagnosis, as measured by a standardised scale. Fifty-two percent of women with DCIS decreased their total physical activity from pre-diagnosis to the first year of diagnosis and 58% of women with invasive breast cancer decreased their total physical activity.	54		
iv	Women with DCIS increased their weight and body fat from the first year of diagnosis (4-12 months after the diagnosis) to their third year of diagnosis (2 years after the initial assessment). Greater weight and body fat gains were found in women with invasive breast cancer (mean 1.7 kg weight gain) compared to women with DCIS (mean 0.9 kg weight gain). Among women with DCIS and invasive breast cancer, greater increases in weight were observed in women who were younger age, postmenopausal, and who decreased their physical activity.	53		

Key findings		Type of study		
		LC	CS	QS
8	Benefits of the diagnosis			
i	The diagnosis had a positive effect on most life-domains for women with DCIS and women with invasive breast cancer when surveyed women 2-3 years after treatment, using a non-standardised scale. The most positive influence of the disease for women with DCIS was seen on women's outlook on life, self-expression/self-improvement, diet, and family relations.		55	
ii	Some women with DCIS felt that the diagnosis had increased their empathy and personal strength.			60
9	Experiences of women with DCIS from culturally and linguistically diverse (CALD) backgrounds			
i	Latina US women had poorer knowledge about DCIS and reported more psychological distress related to their diagnosis than non-Latina white women.			61
ii	The treatment decisions of Chinese Canadian women with DCIS reflected a lack of understanding about DCIS and a preference for mastectomy. Women's treatment decisions were influenced by significant others such as their husbands, Chinese-speaking family physicians, friends and family members. Women reported that they needed more information support in Chinese.			59

4 Discussion

4.1 Methodological considerations

The systematic review found 16 studies including nine observational studies (five longitudinal cohort studies and four cross-sectional studies) and seven qualitative studies that examined the experiences of women diagnosed with DCIS. The review integrated both the qualitative and quantitative evidence from the studies to provide a greater understanding of the experiences of women with DCIS. However, there is very little guidance and few examples of how to synthesise qualitative and quantitative evidence in systematic reviews. This review illustrates the processes of using thematic analysis to synthesise evidence from descriptive studies which include qualitative and quantitative methods. Further research is needed to develop and evaluate methods of synthesising qualitative and quantitative evidence in systematic reviews.

Furthermore, this review demonstrates the importance of conducting qualitative research, particularly in complex areas such as DCIS, and incorporating qualitative research into systematic reviews. The qualitative data in this review were used to provide additional insights to the quantitative data and enabled a greater understanding of the quantitative data about women's experiences of being diagnosed and treated for DCIS. Future research would benefit from using mixed methods research, which combines qualitative and quantitative research methods.⁸⁰

Overall, the quality of the quantitative studies in the review was good. However, the central methodological limitation of the quantitative studies was inadequate demonstration of reliability and validity of the non-standardised measures used in the studies. Future studies should develop measures in consultation with women with DCIS and clinicians and adequately test and report the psychometric qualities of the measures so that the resulting data has a high level of credibility.

The review demonstrates that there is a paucity of quantitative studies that assess the experiences of women with DCIS within the first year after their diagnosis. Given that women with invasive breast cancer have been shown to have a high need for information and support during the first year after their diagnosis,^{4,81} and that information and support needs of women with invasive breast cancer change over time,^{81,82,83} it is important that future studies examine the experiences of women with DCIS within the first year after their diagnosis.

Overall, the quality of the qualitative studies in the review was good. However, some of the qualitative studies inadequately reported important sample characteristics and inadequately evaluated the transferability of the findings to other similar contexts through a discussion of the sampling strategy, the sample characteristics and the study location and settings. The quality of the more recently published studies was better than the older studies^{63,64} which may indicate an improvement in this area. It was not the intention of the quality appraisal in this review to rate the quality of the studies using a rating scale or to exclude any studies due to poor quality as supported by prominent qualitative researchers.^{14,15} In the analysis, the relative contribution of the poorer quality studies^{63,64} to the final analytical themes that were developed and the conclusions of the review were examined (referred to as *sensitivity analyses*).^{12,14} Very few unique themes were developed from the poorer quality studies with the better quality studies contributing most to the development of themes and the conclusions of the review.

4.2 Significance of the review findings

The review of the existing studies demonstrates that there is confusion and misunderstanding among women diagnosed with DCIS about how their diagnosis differs from invasive breast cancer.^{49,51,55-57,60} Women with DCIS are confused about whether they have ‘cancer’ that can result in death and overestimate their risk of local recurrence, metastases and dying from their disease.^{49,51,55-57,60} Inaccurate risk perceptions among women with DCIS are associated with higher levels of anxiety and ‘cancer-specific worry’.^{49,51,60} Women’s confusion about their diagnosis is compounded by the different

terms such as ‘very early breast cancer’, ‘pre-cancer’, ‘carcinoma in situ’, and ‘non-invasive breast cancer’ used by health professionals and used in written information (including information from the Internet) to describe their diagnosis, and by the recommendation of treatments such as a mastectomy.^{49,60,62} There is also evidence from the review that women with DCIS from culturally and linguistically diverse (CALD) backgrounds particularly face difficulty in understanding the implications of their diagnosis.^{59,61}

The central uncertainty for women diagnosed with DCIS is the inability to know whether their DCIS will progress to invasive breast cancer or the time interval in which invasive breast cancer will occur if left untreated. Although knowledge of the uncertainty about DCIS progression to invasive breast cancer is needed for truly informed treatment decision-making, none of the quantitative studies in the review assessed women’s knowledge of this uncertainty. One qualitative study found that some women with DCIS are aware of the uncertainty related to DCIS and question whether treatment is really necessary.⁶⁰ They report a desire for more information about the uncertainty related to DCIS and greater emotional support to cope with this uncertainty. Helping patients ‘manage uncertainty’ has been identified as a key function of doctor-patient communication.^{84,85} Managing uncertainty involves providing information to both inform patients about uncertainty and reduce patients’ perceived uncertainty,^{86,87} and helping patients to emotionally cope with uncertainty.^{88,89}

Furthermore, it is critical that women with DCIS understand the important difference between the prevention goal of treatment for DCIS and the therapeutic goal of treatment for invasive breast cancer so that they can make informed decisions about treatment.^{90,91,92,93} However, this important difference may not be well appreciated by women with DCIS as suggested by women’s overestimated risk perceptions and the lack of understanding among women with DCIS about how their diagnosis differs from invasive breast cancer. There is also evidence from the review that women with DCIS from CALD backgrounds are more likely to choose a mastectomy even in situations when they are recommended to have breast conserving surgery reflecting perhaps a lack of understanding about the purpose of

treatment.⁵⁹ The review demonstrates that there is a paucity of research which directly examines women's understanding about the purpose of treatment for DCIS.

Little is also known about other aspects of treatment decision-making in women with DCIS such as whether women with DCIS experience decisional conflict,⁹⁴ or whether women are satisfied with their involvement in treatment decision-making. Qualitative studies suggest that women with DCIS may experience difficulties in treatment decision-making such as understanding why they are recommended treatment options used to treat invasive breast cancer, especially a mastectomy, when they do not have 'real' breast cancer.^{49,60,62}

Adequate information has been shown to increase patients' understanding,⁹⁵ improve patients' psychological adjustment and perceived quality of life,^{96,97,98} and to ensure participation in treatment decision-making.^{99,100} However, the qualitative studies in this review found that women with DCIS are dissatisfied with the verbal and written information they receive about DCIS.^{49,60-63} Women with DCIS from CALD backgrounds also express a desire for more information about their diagnosis and treatment in their first language.^{59,61} Furthermore, qualitative studies with women with DCIS demonstrate that many women consider the most important source of information is their clinician.^{49,61,63}

Clinicians are responsible for the psycho-social care of their patients as well as their surgical and medical care.¹⁰¹ Providing patients with the opportunity to discuss their feelings has been shown to decrease their psychological distress.^{102,103} Qualitative studies with women with DCIS indicate that women perceive clinicians as a considerable source of emotional support.^{49,60,61,63} However, one qualitative study found that some women with DCIS perceive that health professionals minimise the emotional impact of the diagnosis and treatment of DCIS.⁶⁰ Although women are partly reassured by a better prognosis, women with DCIS feel that they need the same level of emotional support that health professionals provide to women with invasive breast cancer because they are undergoing treatments similar to women with invasive breast cancer and they are also coping with the uncertainty related to DCIS.⁶⁰ Women with DCIS may particularly require emotional support during the first six months after their diagnosis. A large longitudinal cohort study found that

women with DCIS experience a small short term decline in their general mental health in the first six months after their diagnosis.⁵² The study found that women with DCIS have good general mental health in the long term.

Invasive breast cancer and its treatment have been shown to place considerable strain on relationships, particularly in situations where difficulties existed before the diagnosis.⁴ However, only one cross-sectional study assessed the impact of the diagnosis and treatment of DCIS on women's relationships during the first year after diagnosis.⁵⁶ The study surveyed women shortly after surgery and found that only a small percentage of women with DCIS experience a negative impact of the diagnosis and treatment on their relationships, similar to women with invasive breast cancer. In the long term, women with DCIS were found to perceive a *positive* impact of the diagnosis and treatment on their family relations, relatives, spouse, friends and acquaintances, similar to women with invasive breast cancer.⁵⁵ The results are most likely an example of 'posttraumatic growth' or 'benefit finding'.⁷⁹

Social support from a partner, family, friends and support networks has been identified as an important factor in women's adjustment to invasive breast cancer.^{104,105,106} However, only one quantitative study examined social support in women with DCIS.⁵¹ The study found that women with DCIS have a high degree of social support when assessed within six months of the diagnosis. Although the study was a longitudinal cohort study, unfortunately it did not assess social support after the initial enrolment period. A qualitative study found that women with DCIS feel that the support from their family helped them most to cope with their diagnosis and treatment.⁶⁰ Furthermore, patients' emotional or physical problems may disrupt their normal social activities and prevent them from getting the support that would assist their adjustment to their illness.⁷² A longitudinal cohort study found that women with DCIS experience a small short term decline in their social functioning (ability to do their normal social activities) in the first six months after their diagnosis but have good social functioning in the long term.⁵²

Professionally-run support groups,¹⁰⁷ peer support groups,¹⁰⁸ telephone counselling,¹⁰⁹ and Internet support groups¹¹⁰ have been shown to improve the emotional wellbeing of women with invasive breast cancer. However, only two qualitative studies explored the benefits of support groups for women with DCIS.^{49,60} The studies found that, although some women with DCIS benefit from support groups for women with invasive breast cancer, some women with DCIS want support groups (including Internet support groups) specifically for women with DCIS to address their particular issues and concerns and “reduce the isolation of the diagnosis”.

Women diagnosed and treated for invasive breast cancer have been shown to experience a number of treatment-related physical symptoms that affect their quality of life.⁴ Women diagnosed and treated for DCIS might be expected to experience similar treatment-related physical symptoms to women with invasive breast cancer associated with breast surgery, and in some women, radiotherapy and hormonal treatments. The review suggests that women with DCIS may experience a small short term negative impact of treatment in the first six months after their diagnosis but have good long term physical health and functioning.⁵² Furthermore, women with DCIS may experience less negative effects of treatment than women with invasive breast cancer because women with DCIS are less likely to have radiotherapy, sentinel node biopsy or hormonal therapy than women with invasive breast cancer. A cross-sectional study surveyed women 2-3 years after treatment and found that women with DCIS perceive that the disease and treatment has a *positive* impact on their physical health compared to women with invasive breast cancer who perceive that the disease and treatment has a negative impact on their physical health.

Women diagnosed with invasive breast cancer have been shown to experience sexual and body image problems as a result of their diagnosis and treatment.^{111,112} Women diagnosed and treated for DCIS might be expected to experience similar sexual and body image problems to women with invasive breast cancer associated with breast surgery, and in some women, hormonal treatments. None of the studies assessed women’s perceptions of the impact of the diagnosis and treatment of DCIS on their sexuality and body image in the first year after diagnosis. Two quantitative studies^{57,58} and one qualitative study⁶⁰ examined

women's perceptions in the long term and found that women with DCIS perceive that the disease and treatment has a negative impact on their sexuality. However, women with DCIS may experience less negative effects of treatment on their sexuality than women with invasive breast cancer due to differences in treatment. A cross-sectional study surveyed women at 2-3 years after treatment and found that women with DCIS perceive that the disease and treatment has a *positive* impact on their sex life compared to women with invasive breast cancer who perceive that the disease and treatment has a negative impact on their sex life.⁵⁵ Women with DCIS in the study were significantly less likely to have hormonal therapy than women with invasive breast cancer.

Reduced physical activity and weight gain have been shown to be common among women following the diagnosis and treatment of invasive breast cancer.^{113,114} Weight gain is associated with increased risk of developing diabetes and cardiovascular disease.¹¹⁵ Women who are physically active after a diagnosis of invasive breast cancer have also been shown to have a lower risk of cancer recurrence and cancer related death compared with inactive women.^{116,117,118} Two longitudinal cohort studies found that women with DCIS decrease their physical activity and increase their weight and body fat following the diagnosis.^{53,54} However, greater weight and body fat gains were found in women with invasive breast cancer compared to women with DCIS.⁵³ Among women with DCIS and invasive breast cancer, greater increases in weight were found in women who are of a younger age, postmenopausal, and who decrease their physical activity.⁵³ Women with DCIS are more likely to decrease their physical activity if they have a mastectomy or are more anxious.⁵⁰

4.3 Future research about the experiences of women with DCIS

This review demonstrates that further research is needed in four important areas. First, there is a paucity of evidence about women's understanding of the central uncertainty of the progression of DCIS to invasive breast cancer. It is critical that women understand this uncertainty so that they can make informed decisions about treatment. Furthermore, patients have a legal and moral right to accurate information about their diagnosis and the doctor has a duty to disclose this information to the patient.¹¹⁹ Little is also known about

the emotional impact on women of coping with this uncertainty. Further research is required to examine women's understanding of the uncertainty related to the natural history of DCIS and the potential consequences of women's understanding of this uncertainty in terms of its impact on treatment decision-making and women's psychological health. Such research would greatly assist in developing interventions to improve communication about the uncertainty related to the natural history of DCIS and improve the well-being of women with DCIS.

Second, it is also critical that women with DCIS understand the implications of a non-invasive cancer so that they can make informed decisions about treatment. Women must understand the important difference between the prevention goal of treatment for DCIS and the therapeutic goal of treatment for invasive breast cancer. However, there is a paucity of research that directly examines women's knowledge about the purpose of treatment. Furthermore, little is known about other aspects of treatment decision-making in women with DCIS such as whether women with DCIS experience decisional conflict or whether women are satisfied with their involvement in treatment decision-making. Further research is required that examines the treatment decision-making experiences of women with DCIS. Qualitative studies may be particularly helpful in understanding the complexities of treatment decision-making^{120,121,122} and may be especially important in examining the experiences of women with DCIS given the challenges involved in DCIS. Further research that examines the treatment decision-making experiences of women with DCIS could provide vital information needed to improve treatment decision-making in women with DCIS.

Third, the review demonstrates that there is a paucity of evidence about the specific information needs of women with DCIS. While qualitative studies with women with DCIS found that women are dissatisfied with the verbal and written information they receive about their diagnosis,^{49,60-63} little is known about the specific information needs of women with DCIS related to aspects of their diagnosis, prognosis and treatment. There is limited evidence from quantitative studies with women with DCIS about women's information needs. Two cross-sectional studies found that most women with DCIS are satisfied with the

information they receive about their diagnosis and treatment.^{57,58} However, the significance of the results of the studies are limited by the long time period between diagnosis and participation in the surveys and the lack of assessment of women's satisfaction with information about various aspects of the diagnosis, prognosis and treatment. Further research is required that examines the specific information needs of women with DCIS. Such research is vital to ensure that the information needs of women with DCIS are met. Meeting the information needs of women with DCIS is likely to improve women's understanding about their diagnosis and decrease women's psychological distress.

Fourth, it is well recognised that patients from culturally and linguistically diverse (CALD) backgrounds have their own unique experiences, behaviours, and beliefs in relation to health and illness.¹²³ Furthermore, patients may experience difficulty in comprehending information in the medical consultation if they have limited English fluency.¹²⁴ This review demonstrates that a lack of understanding about DCIS may be even more pronounced in women from CALD backgrounds and that women from CALD backgrounds may experience greater psychological distress due to this lack of understanding about their diagnosis. However, this review reflects only the experiences of women with DCIS from two CALD communities in Canada⁵⁹ and the USA.⁶¹ Considering the number of CALD communities, particularly living in Australia¹²⁰ there is a need for further research to understand the experiences and challenges that face women with DCIS from other CALD backgrounds. Such research will help to ensure that communication is sensitive to women's cultural values and optimises women's understanding of their diagnosis, and that women are provided with appropriate emotional support. Furthermore, there is a need to explore the experiences of Australian Aboriginal and Torres Strait Islander women with DCIS. It is recognised that women from Aboriginal and Torres Strait Islander backgrounds have specific health care experiences and needs.^{4,125,126} Research exploring the experiences of Australian Aboriginal and Torres Strait Islander women with DCIS and women with DCIS from other CALD backgrounds would provide important information to guide the development of culturally appropriate interventions to improve communication and improve the health outcomes of these women.

4.4 Limitations of the review

The involvement of additional researchers in the process of appraising the quality of the studies and synthesising the data in this review would have enabled a greater examination of the author's views of the data and increased understanding of the data (as appropriate to a constructivist or interpretive paradigm).^{14,37}

This review includes only peer-reviewed papers published in the English language and therefore does not reflect any unpublished literature or any literature concerning the experiences of women with DCIS from CALD backgrounds that may be published in languages other than English.

4.5 Conclusions

The systematic review in this chapter presents a unique synthesis of the emerging literature about the experiences of women diagnosed with DCIS. The review demonstrates that there is confusion and misunderstanding among women with DCIS about how their diagnosis differs from invasive breast cancer. Inaccurate risk perceptions among women with DCIS are associated with higher levels of anxiety and 'cancer-specific worry'. Women with DCIS also report that they want more written and verbal information about their diagnosis.

The review demonstrates that women with DCIS perceive clinicians as a considerable source of emotional support. Women want to be reassured about their good prognosis but report that they do not want health professionals to minimise the impact of the diagnosis and treatment of DCIS. In addition to support from health professionals, women indicate that they want support groups (including Internet support groups) specifically for women with DCIS to address their particular needs and concerns.

The review suggests that women with DCIS have good long term general mental health, and physical health and functioning. However, there is evidence that some women experience sexual and body image problems, and some women decrease their physical

activity and increase their weight and body fat following the diagnosis and treatment of DCIS.

Overall, the review found that there are a small number of studies which examine the experiences of women diagnosed with DCIS. In particular, further research is required to examine women's understanding of the uncertainty related to the natural history of DCIS, the experiences of treatment decision-making in women with DCIS, the specific information needs of women with DCIS, and the experiences of Australian Aboriginal and Torres Strait Islander women with DCIS and women with DCIS from other CALD backgrounds. Such research would greatly assist in the development of appropriate interventions to ensure the psycho-social and physical wellbeing of women with DCIS.

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Chapter 2

Knowledge, satisfaction with information, decisional conflict and psychological morbidity amongst women diagnosed with ductal carcinoma in situ (DCIS): a cross-sectional survey of women diagnosed with DCIS in Australia

Appendix 2.1

De Morgan S, Redman S, D'Este C, Rogers K. Knowledge, satisfaction with information, decisional conflict and psychological morbidity amongst women diagnosed with ductal carcinoma in situ (DCIS). Patient Educ Counsel 2011;84:62-68.

1 Introduction

Understanding the experiences of women with DCIS is necessary for developing guidelines and interventions for improving care.^{1,2,3} However, the systematic review described in *Chapter 1* demonstrates that there are only a small number of studies that examine the experiences of women diagnosed with DCIS. In particular, there is a paucity of quantitative studies examining the experiences of women with DCIS within the first year after their diagnosis using reliable measures that are appropriate to women with DCIS.

This chapter describes a cross-sectional survey of women diagnosed with DCIS in Australia (N=144) within the first year after their diagnosis. The survey was developed in consultation with health professionals and women with DCIS and the survey items were tested for reliability. The survey included open questions to provide qualitative data that could add meaning and understanding to the quantitative data,⁴ considered to be particularly important in this study due to the complexities and challenges of DCIS.

This study examines a number of important areas not examined in the studies described in the review in *Chapter 1*. Firstly, the review found that women with DCIS overestimate their risk of local recurrence, metastases and dying from their disease.^{5,6,7,8} However, none of the quantitative studies in the review examined women's knowledge of the uncertainty about DCIS progression to invasive breast cancer, and the critical difference between the prevention goal of DCIS treatment and the therapeutic goal of invasive breast cancer treatment. Furthermore, the qualitative studies in the review show that women with DCIS are confused about whether they have 'cancer' that can result in death.^{9,10} However, none of the quantitative studies examined the content of women's confusion about their diagnosis.

Secondly, the qualitative studies in the review show that many women with DCIS are dissatisfied with the information about their diagnosis.^{10,11,12,13} However, there is limited evidence from quantitative studies about women's satisfaction with information.^{7,14} Women's satisfaction with information has been assessed in terms of satisfaction with 'information from doctors' and 'information related to future health problems';⁷ and

satisfaction with ‘information about the disease’, ‘information about surgery’, and ‘information about radiotherapy’. However, none of the quantitative studies in the review examined women’s satisfaction with information about different aspects of the diagnosis and treatment such as information about the type of breast disease women had, whether women’s breast disease could metastasize, the various treatment options, the side effects of treatment, breast reconstruction, the impact of treatment on their sexuality, the effectiveness of treatment, the prognosis without treatment, the risk of a daughter developing breast cancer, and follow-up after treatment.

Thirdly, the qualitative studies in the review show that some women with DCIS experience difficulties in treatment decision-making such as understanding why they are recommended treatment options used to treat invasive breast cancer, especially a mastectomy, when they do not have ‘real’ breast cancer.^{9,10,12} However, none of the quantitative studies in the review assessed decisional conflict¹⁵ in women with DCIS. High decisional conflict has been shown to result in delayed decision-making and feeling emotionally distressed by the decision.¹⁶

Fourthly, cancer-specific worry has been shown to be distinct from risk perception^{17,18} and anxiety and depression,^{19,20} and has been assessed in two quantitative studies in the review in terms of the level of ‘worry about getting breast cancer’⁷ and the level of ‘intrusive or avoidant thoughts’ in response to the diagnosis.^{5,7} However, none of the quantitative studies in the review investigated the frequency of worry about the various breast cancer related events specific to DCIS such as worry about the breast disease spreading and worry about dying from the breast disease.

Lastly, the review demonstrates that women with DCIS experience psychological distress related to their diagnosis and treatment.^{5,8-10,21} However, none of the quantitative studies in the review examined whether women received support from psycho-social health professionals.

1.1 Aims of the study

This study examines knowledge, satisfaction with information, treatment decision-making, and psychological morbidity among women with DCIS. The author was particularly interested in the potential causes and impact of not knowing that DCIS cannot metastasize or confusion about whether DCIS can metastasize, as these issues had emerged as central concerns in the author's previous qualitative study with women with DCIS.¹⁰

The aims of the study (as shown in *Table 2.1*) are as follows:

1. To examine the experiences of women with DCIS in terms of: a) women's knowledge about DCIS; b) women's satisfaction with information; c) women's experience of treatment decision-making; and d) women's psychological morbidity
2. To examine whether any of the following factors are associated with poor knowledge about DCIS, that is, not knowing that DCIS cannot metastasize:
 - a) *Factors that may relate to the causes of poor knowledge including:* a range of demographic factors; not receiving or not being satisfied with information about whether DCIS can metastasize; and consultation with a psycho-social health professional
 - b) *Factors that may relate to the impact of poor knowledge including:* worry about dying from the breast disease or worry about other breast cancer-related events; confusion about whether DCIS can metastasize; anxiety and depression; decisional conflict; and having a mastectomy
3. To examine whether any of the following factors are associated with confusion about DCIS, that is, confusion about whether DCIS can metastasize:

- a) *Factors that may relate to the causes of confusion including:* a range of demographic factors; not receiving or not being satisfied with information about whether DCIS can metastasize; and consultation with a psycho-social health professional
- b) *Factors that may relate to the impact of confusion including:* worry about dying from the breast disease or worry about other breast cancer-related events; anxiety and depression; decisional conflict; and having a mastectomy

Table 2.1: Aims of the study

Aim 1 To examine the experiences of women with DCIS in terms of:

- a) women's knowledge about DCIS including:
 - women's understanding about whether DCIS could metastasize
 - the natural history of DCIS
 - the aim of treatment
 - the prognosis after treatment
 - b) women's satisfaction with information including:
 - information about the type of breast disease women had
 - whether women's breast disease could metastasize
 - the treatment options
 - the side effects of treatment
 - breast reconstruction
 - the impact of treatment on women's sexuality
 - the effectiveness of treatment
 - the prognosis without treatment
 - the risk of a daughter developing breast cancer
 - follow-up after treatment
 - c) women's experience of treatment decision-making including:
 - decisional conflict
 - perceived level of involvement in treatment decision-making
 - satisfaction with the perceived level of involvement in treatment decision-making
-

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-
- d) women's psychological morbidity including:
- cancer-specific worry
 - anxiety and depression
 - support from psycho-social health professionals
-

Aim 2 To examine whether any of the following factors are associated with poor knowledge about DCIS, that is, not knowing that DCIS cannot metastasize:

- a) potential causes:
- demographic factors (older age, residing in rural or remote area, lower education levels, not being employed, or having a culturally and linguistically diverse (CALD) background)
 - not receiving or not being satisfied with information about whether DCIS can metastasize
 - consultation with a psycho-social health professional
- b) potential impact:
- worry about dying from the breast disease or worry about other breast cancer-related events
 - anxiety and depression
 - confusion about whether DCIS can metastasize
 - decisional conflict
 - confusion about whether DCIS can metastasize
 - having a mastectomy
-

Aim 3 To examine whether any of the following factors are associated with confusion about DCIS, that is, confusion about whether DCIS can metastasize:

- a) potential causes:
- demographic factors (older age, residing in rural or remote area, lower education levels, not being employed, or having a culturally and linguistically diverse (CALD) background)
 - not receiving or not being satisfied with information about whether DCIS can metastasize
 - consultation with a psycho-social health professional
- b) potential impact:
- worry about dying from the breast disease or worry about other breast cancer-related events
 - anxiety and depression
 - decisional conflict
 - having a mastectomy
-

2 Methods

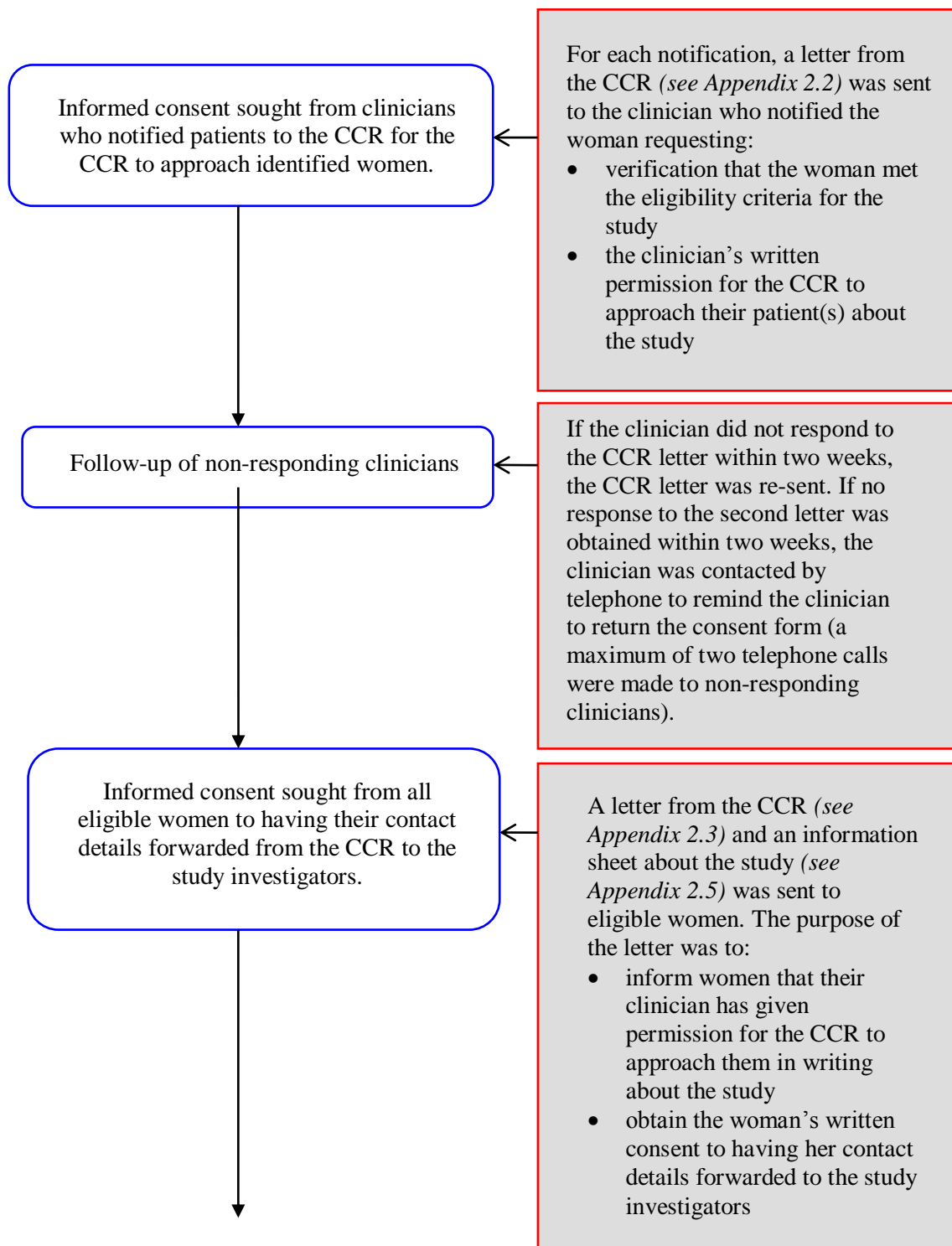
2.1 Study population

Women who were eligible to participate in the study were diagnosed with ductal carcinoma in situ (DCIS) in NSW, Australia, and were notified to the NSW Central Cancer Registry (NSWCCR) from 1 January 2001 to 31 December 2001. Notification of cancer to the NSWCCR is legally required of all pathology laboratories, hospitals and radiotherapy facilities in NSW. Women were excluded if they had a previous or simultaneous diagnosis of invasive breast cancer, or micro invasive disease which the NSWCCR codes as invasive breast cancer. In addition, women were excluded if they were deemed by their doctor to be too ill or unable to speak English adequately for the self-completed survey or were no longer residing in NSW. Women were recruited to the study 6 to 12 months after their diagnosis.

2.2 Sampling and participation

Confirmation of the woman's eligibility for the study was sought from doctors who notified women to the NSWCCR (*see Appendix 2.2*). Of the 290 women who were identified by the NSWCCR, 234 were deemed eligible by their doctor to participate in the study. Eligible women were informed about the study and asked for their consent to having their contact details forwarded from the CCR to the study investigators (*see Appendix 2.3*). Consenting women (n=159) were sent a letter (*see Appendix 2.4*), information sheet about the study (*see Appendix 2.5*), and the survey *About your diagnosis* (*see Appendix 2.6*). Non-responding clinicians and women were followed-up by a letter and two telephone calls. The number of returned completed surveys was 144. The overall response rate was 62%. *Figure 1* outlines the sampling procedure and *Figure 2* outlines the participation in the study. The final survey was intended to take an average of 30 minutes to complete. Ethics approval to conduct the study was granted by the NSW Cancer Council Ethics Committee.

Figure 1: Sampling procedure for the study



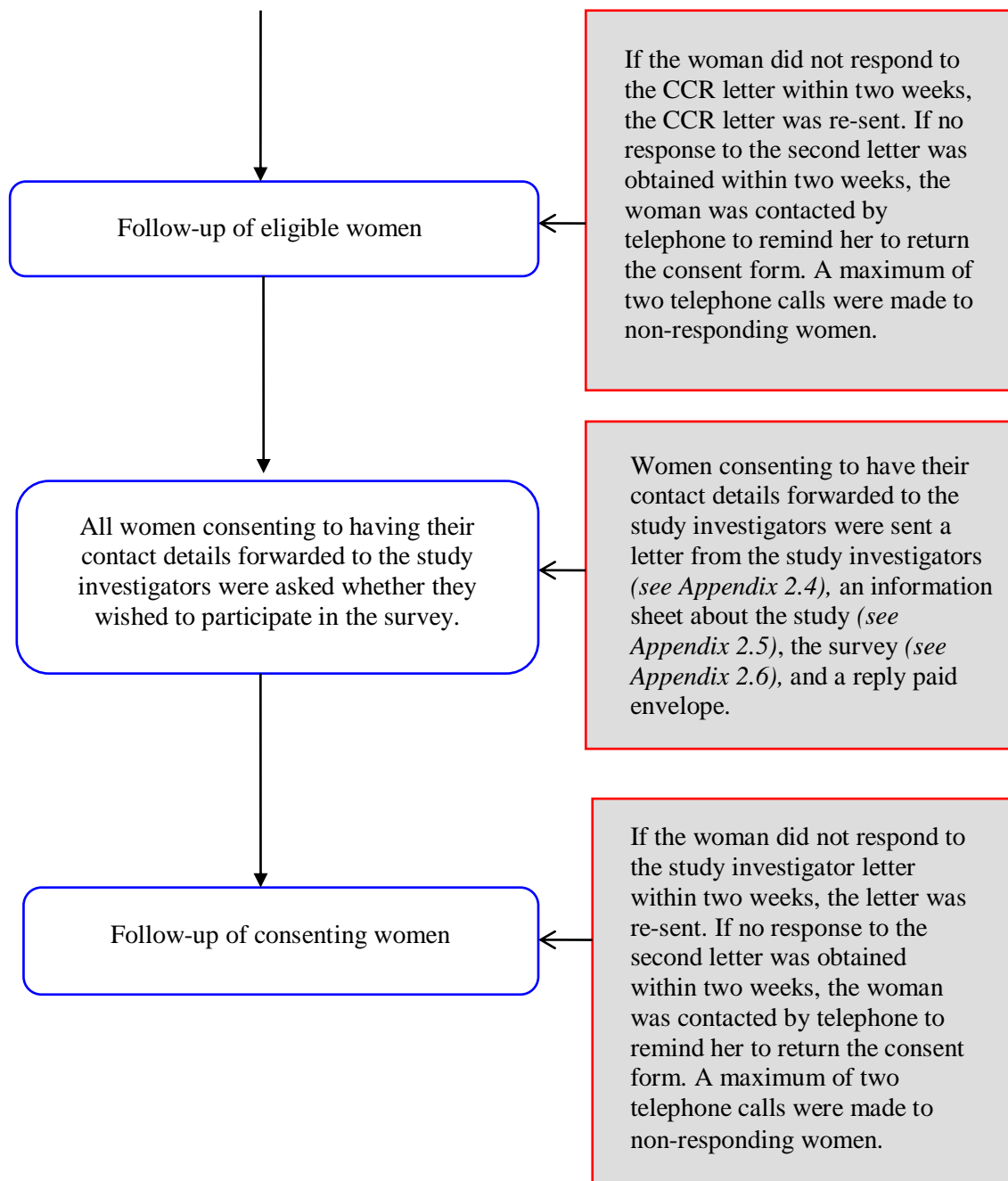
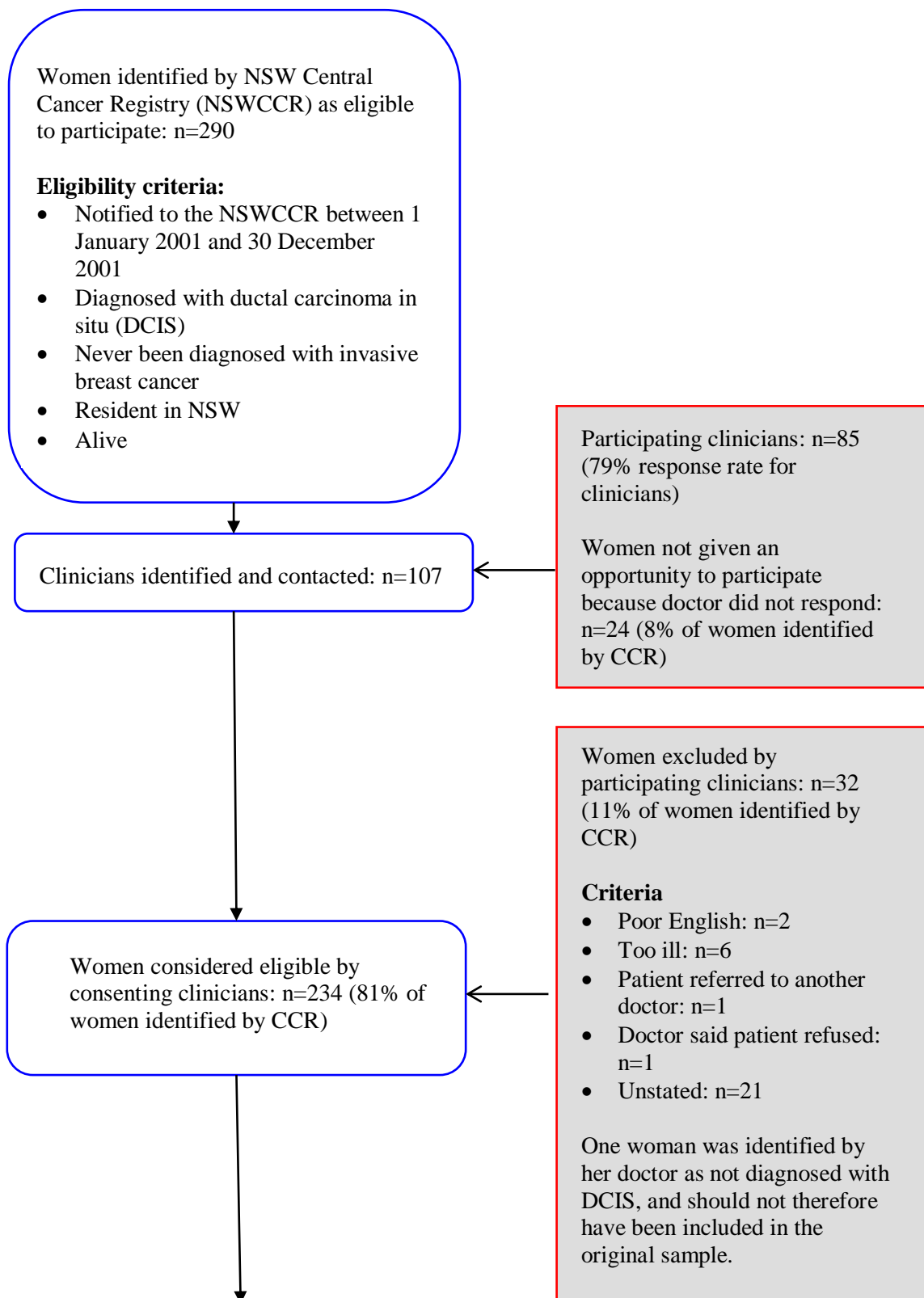
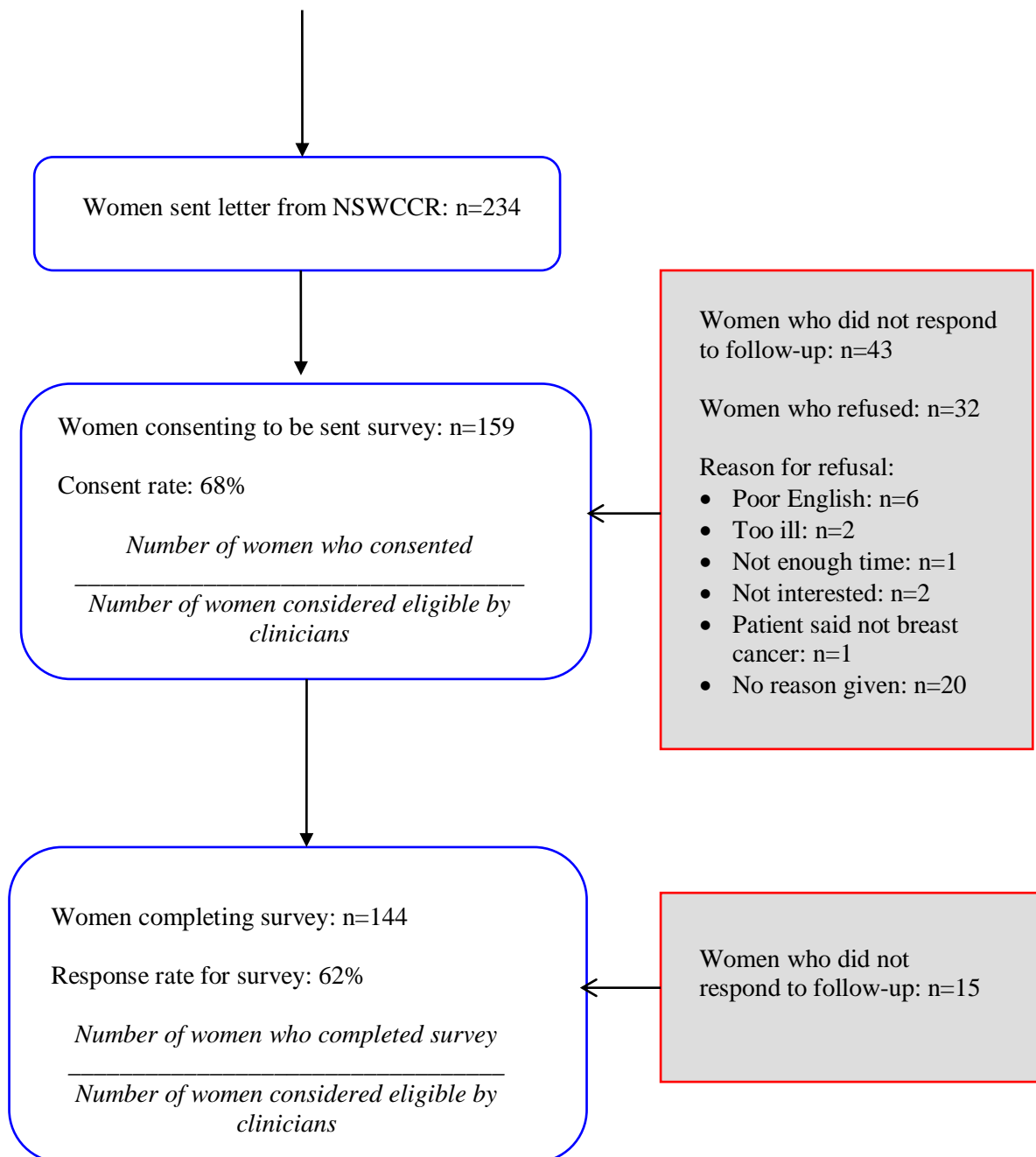


Figure 2: Participation in the study





2.3 Comparison of participants and eligible non-participants

There were no significant differences between participants and eligible non-participants according to age, area of residence, or country of birth as shown in *Table 2.2*.

Participants included women who returned the completed survey (n=144) and eligible non-participants (n=149) included women who were initially identified by the CCR as eligible to participate in the study but who did not participate in the study. Eligible non-participants included women whose doctor did not return eligibility forms for inclusion in the study, women whose doctor deemed them ineligible to participate in the study, women who refused to participate in the study, women who withdrew from the study, and women who did not return a completed survey.

Table 2.2: Comparison of participants and eligible non-participants according to age, area of residence, or country of birth

		women n (%)	eligible non- participants n (%)	χ^2 (df=1)	p value
i	Age				
	<50yrs	61 (47%)	70 (53%)	0.897	0.639
	50-69years	61 (53%)	55 (47%)		
	≥ 70 yrs	21(49%)	22 (51%)		
ii	Residence			0.001	0.980
	major city	100 (50%)	103 (51%)		
	regional/ remote	43 (50%)	44 (51%)		
iii	Country of birth			0.892	0.345
	Australia	137 (50%)	139 (50%)		
	Not Australia	6 (38%)	10 (63%)		

Missing values for each item: 0-2 (0-1%)

2.4 Measures

2.4.1 *Measures developed by the author*

Due to a lack of DCIS-specific measures reported in the literature, the author developed items about knowledge, confusion, satisfaction with information, worry about the DCIS diagnosis, satisfaction with perceived level of involvement in treatment decision-making, and psycho-social support. The items were developed from the author's previous qualitative study with women with DCIS,¹⁰ the literature concerning the quality of life and psycho-social well-being of women with DCIS and women with invasive breast cancer, and the general communication literature. The developed items were reviewed by a multidisciplinary team that included surgeons, a radiation oncologist, a psychiatrist, a breast nurse, senior academic health researchers, and seven women diagnosed with DCIS including one woman who was actively involved in breast cancer support networks. The individual items were not intended to be combined into summary scores or scales. Open questions in most sections of the survey enabled women to make additional comments.

As these survey items were bespoke, test-retest reliability was assessed. The test-retest reliability of the survey items was calculated using the weighted or simple Kappa coefficient statistic (95% CL). The weighted kappa coefficient statistic was used for ordinal scales with ordering of the values and the simple kappa coefficient statistic was used for categorical variables where there was no ordering of the values.

Thirty-four women (24% of the sample) who were amongst the first 40 women to return the initial survey participated in the test-retest reliability of the survey items. The test-retest reliability assessment demonstrated that seventy per cent of the survey items scored above 0.50 in Kappa analysis²² (*see Appendix 2.7 for test-retest reliability calculations for all survey items*).

2.4.1A Knowledge

Knowledge items were developed to assess women's understanding about whether DCIS could metastasize, the natural history of DCIS, the aim of treatment, and the prognosis after treatment. Twelve knowledge items were included with response options: *true*, *false* and *don't know*. The first three knowledge items did not have a correct answer and explored the terms women used to describe their diagnosis including: *breast cancer*, *early stage breast cancer*, *pre-cancer*, *non-invasive breast cancer*. One of the items assessed knowledge about whether DCIS can metastasize and was selected apriori for inclusion in the logistic regression analyses. An open question enabled women to make additional comments about their diagnosis.

2.4.1B Confusion

Confusion is distinct from knowledge and has been described as one of the dimensions of emotional distress.^{23,24} Confusion items were developed to assess the level and content of women's 'bewilderment' about aspects of their diagnosis such as the type of breast disease they had, whether their breast disease could metastasize, why they needed the type of treatment they had, and their prognosis with or without treatment. Seven confusion items were included with response options: *very confused*, *a little confused* and *did not feel confused*. One of the items assessed confusion about whether DCIS can metastasize and was selected apriori for inclusion in the logistic regression analyses. An open question enabled women to make additional comments about any confusion they were experiencing.

2.4.1C Information

Information items were developed to assess women's satisfaction with information about the type of breast disease they had, whether their breast disease could metastasize, the treatment options, the side effects of treatment, breast reconstruction, the impact of treatment on their sexuality, the effectiveness of treatment, their prognosis without treatment, the risk of a daughter developing breast cancer, and follow-up after treatment.

Eleven information items were included with response options: *I would have liked more information, I received as much information as I needed, I received too much information, I didn't want any information and I would have liked information.* An open question enabled women to make additional comments about their satisfaction or dissatisfaction with information.

2.4.1D Cancer-specific worry

Worry items were developed to assess the frequency of worry about breast cancer-related events specific to the DCIS diagnosis. Four worry items assessed the frequency of worry about the breast disease metastasizing, dying from the breast disease, developing breast cancer in the same breast (or chest wall), and developing breast cancer in the opposite breast. Response options included: *rarely or never, sometimes or occasionally, often, and most of the time.* An open question enabled women to provide additional comments about any worry they were experiencing about their diagnosis.

2.4.1E Satisfaction with perceived level of involvement in treatment decision-making

One item was developed to assess women's satisfaction with their perceived level of involvement in treatment decision-making and included response options: *I would have preferred to have been more involved in deciding about my treatment, I am happy with the amount of involvement I had in deciding about my treatment, and I would have preferred to be less involved in deciding about my treatment.*

2.4.1F Psycho-social support

Three psycho-social support items were developed to assess whether women had the opportunity to consult with a counsellor, breast nurse, psychologist or psychiatrist and included *yes* and *no* response options.

2.4.2 *Standardised measures*

2.4.2A *Decisional conflict*

Decisional conflict was measured using the Decisional Conflict Scale (DCS).¹⁵ Decisional conflict can be described as a state of uncertainty about which course of action to take when choices among competing actions involve risk, loss, regret or challenge to personal values. The decisional conflict scale measures personal perceptions of : a) uncertainty in choosing options; b) modifiable factors contributing to uncertainty such as feeling uninformed, unclear about personal values and unsupported in decision-making; and c) effective decision-making such as feeling the choice is informed, values-based, likely to be implemented and expressing satisfaction with the choice. The DCS is a 16 item Likert scale that has demonstrated validity and reliability in a variety of population groups. The scale has five subscales: certainty; informed; values; social support; and perceived effective decision. The overall scores and subscores range from 0 (no decisional conflict) to 100 (extremely high decisional conflict). Scores exceeding 37.5 are associated with delayed decision-making or feeling unsure about implementation.²⁵

2.4.2B *Anxiety and depression*

Anxiety and depression were assessed using the 14 item Hospitalized Anxiety and Depression Scale (HADS). Scores of 11 or greater on the HADS anxiety and depression subscales were considered indicative of substantial anxiety or depression, respectively, based on the validation of this measure.²⁶ Scores of eight or greater were classified as including cases and doubtful cases and have been shown to improve the sensitivity of the HADS scale, particularly the HADS-Anxiety Scale^{27,28} and have identified patients with prolonged psychological distress.²⁹

2.4.2C Perceived level of involvement in treatment decision-making

The women's perceived level of involvement in treatment decision-making was measured using the Control Preferences Scale that has demonstrated validity and reliability in studies with cancer patients.³⁰ Response options included *I made the decision using all that I knew and learnt about the treatment; I made the decision but strongly considered the doctor's opinion; the doctor and I made the decision together on an equal basis; the doctor made the decision but strongly considered my opinion; and the doctor made the decision using all that he or she knew about treatments.*

2.4.3 Participant characteristics

Participants characteristics including: date of diagnosis; age; residence; first language; Aboriginal or Torres Strait Islander origin; education; relationship status; employment status; usual occupation; whether any close family members or close friends were diagnosed with breast cancer; and type of treatment were included in the survey.

2.5 Data analysis

Numbers and percentages are presented for socio-demographic and treatment characteristics of the sample and for the responses to items in the survey.

The author selected knowledge about whether DCIS can metastasize and confusion about whether DCIS can metastasize as the two main outcomes of interest because understanding that DCIS cells lack the capacity to metastasize, and therefore cannot cause death, is the central issue in understanding how DCIS differs from invasive breast cancer, and our qualitative work showed that many women were confused about this aspect.

Factors associated with the two main outcomes of interest were initially investigated using chi-square analyses followed by logistic regression analysis to adjust for potential confounders. Variables were included in the logistic regression analysis if they had a p

value of 0.25 or less on univariate analyses and backward stepwise regression used to exclude variables with a p values of > 0.1 on Wald tests. The goodness-of-fit of the model was tested using the Hosmer-Lemeshow tests.³¹ Factors of interest included the following:

- 1) Participant characteristics: age (<60 yrs vs ≥ 60 yrs); residence (urban vs rural/remote); first language spoken (English vs non-English); education (tertiary vs non- tertiary); employment (employed vs not employed); relationship status (in a relationship vs not in a relationship); and knowing someone close who had breast cancer (yes vs no).
- 2) Treatment: lumpectomy only (yes vs no), mastectomy only (yes vs no); lumpectomy and mastectomy (yes vs no); no surgery after biopsy (yes vs no); radiotherapy (yes vs no); and hormonal therapy eg Tamoxifen (yes vs no)
- 3) Information: satisfaction with information about DCIS metastasizing (yes vs no); and receiving information about DCIS metastasizing (yes vs no).
- 4) Worry relating to the diagnosis: worry about DCIS metastasizing (yes vs no); worry about dying from the breast disease (yes vs no); worry about developing breast cancer in the same breast or chest wall (yes vs no); and worry about developing breast cancer in the opposite breast (yes vs no).
- 5) Anxiety and depression: anxiety by HADS (definite case ≥ 11 vs non-case /doubtful case <11 , definite case/ doubtful case ≥ 8 vs non-case <8 ; note, no tests of association were performed using depression scores from the HADS as the number of cases for depression was less than 10%);
- 6) Decisional conflict: Decisional Conflict Scale (high decisional conflict >37.5 vs low decisional conflict ≤ 37.5);
- 7) Consultation with a psycho-social health professional: consultation with a breast nurse (yes vs no); and consultation with a counsellor (yes vs no).

SAS Statistical software (Version 9.13) was used for all statistical analysis and a 5% significance level was used. The qualitative data from open questions were coded into themes and sub-themes using thematic analysis³² and have been reported briefly in the results section.

3 Results

3.1 Sample characteristics

The characteristics of the sample are outlined in *Table 2.3*. Age at diagnosis ranged from 27 to 79 years and the mean age was 56 years old (standard deviation 10.34). Most women lived in a city, were currently in a relationship, and spoke English as their first language. Approximately half of the women had a tertiary education and approximately half of the women were currently employed.

Most women had surgery after their initial biopsy of the DCIS lesion. Approximately half of women had breast conserving surgery (lumpectomy) only, 23% had a mastectomy only, and 13% had breast conserving surgery and a mastectomy. Approximately one third of women had radiotherapy, and 13% of women were taking hormonal therapies such as Tamoxifen.

Table 2.3: Characteristics of study sample (N=144)

	n (%)
Age	
Range	27-79 yrs
< 60 years	78 (57%)
≥ 60 years	60 (43%)
Mean	56.41 yrs
Standard deviation	10.34
Area of residence	
Major city	101 (70%)
Rural/ Remote	40 (28%)
Educational level	
Non-tertiary	69 (48%)
Tertiary	73 (51%)

continued next page

	n (%)
Employment	
<i>Not employed</i> (Home duties/ retired/ unable to work)	73 (51%)
<i>Employed</i> (Employed P/T or F/T/ self-employed)	70 (49%)
Relationship status	
<i>In a relationship</i> (Married/ de facto)	109 (76%)
<i>Not in a relationship</i> (Divorced or separated/ widowed/ single)	34 (24%)
English as first language	131 (91%)
Aboriginal or Torres Strait Islander	1 (1%)
Family member/ close friend with breast cancer	79 (55%)
Treatment	
<i>Lumpectomy only</i>	75 (52%)
<i>Mastectomy only</i>	33 (23%)
<i>Lumpectomy and mastectomy</i>	18 (13%)
<i>No additional surgery (after biopsy)</i>	18 (13%)
<i>Radiotherapy</i>	56 (39%)
<i>Axillary lymph node removal</i>	25 (17%)
<i>Hormonal therapy eg Tamoxifen</i>	18 (13%)
Missing data for <i>age at diagnosis</i> n=8 (6%). Missing data in other categories ranged from 0-3 (0-2%).	

3.2 Aim 1: the experiences of women with DCIS

Relevant themes and subthemes developed in *Chapter 1* to describe the review findings were used to describe the experiences of women with DCIS in this study. The themes identified in this study include: *knowledge* (Section 3.2.1); *information needs* (Section 3.2.2); *treatment decision-making* (Section 3.2.3); and *psychological morbidity* (Section 3.2.4).

Table 2.37 (see Page 171) provides a summary of the key findings of the study.

3.2.1 Knowledge

3.2.1A Description of the diagnosis

Table 2.4 outlines how women described their diagnosis (women could describe their diagnosis using multiple terms). Most women described their diagnosis as an early stage breast cancer. However, most women also described their diagnosis as a breast cancer contained in the milk ducts of the breasts and 59% described their diagnosis as a non-invasive breast cancer. Forty-four per cent of women described their diagnosis as a pre-cancer.

Table 2.4: Women's description of their diagnosis

Description of the diagnosis		Answered True <i>n (%)</i>	Answered False <i>n (%)</i>	Answered Don't know <i>n (%)</i>
i	I had breast cancer	96 (69%)	35 (25%)	8 (6%)
ii	I had an early stage breast cancer	100 (73%)	25 (18%)	12 (9%)
iii	I had a pre-cancer	60 (44%)	44 (32%)	32 (24%)
iv	I had a non-invasive breast cancer	78 (59%)	31 (23%)	24 (18%)
v	I had breast cancer that was contained in the milk ducts of my breasts	101 (72%)	19 (14%)	20 (14%)
vi	I had an advanced breast cancer	1 (1%)	126 (92%)	10 (7%)

Responses not mutually exclusive. Missing data for each item ranged from 4-11 (3-8%).

3.2.1B Knowledge about DCIS

Table 2.5 outlines women's knowledge about key aspects of their diagnosis and prognosis. Sixty per cent of women thought that DCIS could metastasize, 27% did not know, and only 12% knew that DCIS cannot metastasize. Only 19% of women were aware of the natural history of DCIS, that is, that not *all* women with DCIS would develop invasive breast

cancer if left untreated. Almost half of women thought that *all* women diagnosed with DCIS would develop invasive breast cancer if left untreated, and approximately one third of women did not know whether *all* women diagnosed with DCIS would develop invasive breast cancer if left untreated. Most women understood that the aim of treating DCIS is to remove the DCIS and prevent it from developing into the type of breast cancer that can spread to other parts of the body.

Table 2.5: Women's knowledge about DCIS

Knowledge about DCIS		Correct answer <i>n</i> (%)	Incorrect answer <i>n</i> (%)	Answered Don't know <i>n</i> (%)
i	If left untreated, DCIS can develop into the type of breast cancer that can spread to other parts of the body	108 (78%)	6 (4%)	25 (18%)
ii	If left untreated, DCIS alone cannot spread to other parts of the body	17 (12%)	84 (60%)	38 (27%)
iii	<u>All</u> women diagnosed with DCIS if they are not treated will develop the type of breast cancer that can spread to other parts of the body	27 (19%)	67 (48%)	45 (32%)
iv	The aim of treating DCIS is to remove the DCIS and prevent it from developing into the type of breast cancer that can spread to other parts of the body	123 (88%)	1 (1%)	16 (11%)
v	Even after treatment, there is still a chance that DCIS or breast cancer may come back in the breast (or in the chest wall if your breast was removed)	86 (61%)	16 (11%)	38 (27%)
vi	I have a greater chance of developing breast cancer in the other breast than women who have not been diagnosed with DCIS	61 (44%)	31 (22%)	46 (33%)

Missing data for each item ranged from 4-6 (3-4%)

Women's lack of understanding about DCIS was highlighted in their responses to the open questions in the survey.

"I'm really not sure of any of the answers to these [knowledge] questions."

Women reported feeling unsure about key aspects of the diagnosis and prognosis.

"I am not sure of the type of cancer DCIS is, if it is aggressive or not, or if it is likely to come back."

I'm not sure if having DCIS puts me at higher risk of getting it [invasive breast cancer] or not."

Women also reported that they had not heard about DCIS prior to their diagnosis and that this made the diagnosis more shocking and difficult to understand.

"Before I was diagnosed with DCIS I had never heard of it."

3.2.2 Information needs

3.2.2A Satisfaction with information about the diagnosis and treatment of DCIS

Table 2.6 outlines the number of women who were *not* satisfied with information about their diagnosis and treatment due to inadequate information, that is, the number of women who responded *I would have liked information* or *I would have liked more information* to information items. Only one woman reported that she was *not* satisfied with information about the diagnosis and treatment due to receiving *too much* information about the following: the side effects of treatment; breast reconstruction; daughter developing breast cancer; and check-ups.

Approximately half of women would have like more information about whether their breast disease could metastasize, one third of women would have liked more information about the type of breast disease they had, 44% would have liked more information about the chances of local recurrence after treatment, and one third of women would have liked more information about the chances of their breast disease metastasizing or dying from the breast disease if they did or did not have treatment. In addition, 44% of women would have liked more information about the risk of their daughter(s) developing breast cancer. A higher proportion of women were more satisfied with the information they received about most aspects of their treatment and follow-up than about their diagnosis.

Table 2.6: Satisfaction with information about the diagnosis and treatment of DCIS

<i>Diagnosis</i>		Not Satisfied* n (%)
i	The type of breast disease you had	48 (34%)
ii	Whether or not you have the type of breast cancer that can spread to other parts of your body	74 (54%)
iii	The chances of your breast disease spreading to other parts of your body or dying from your breast disease if you did or did not have treatment	51 (36%)
iv	The risk of your daughter(s) developing breast cancer	56 (44%)
<i>Treatment</i>		
i	All of the possible treatments for your breast disease	30 (22%)
ii	All the possible side effects of treatment(s) for your breast disease	49 (36%)
iii	Breast reconstruction	28 (21%)
iv	The impact of your treatment(s) on your sexuality	34 (26%)
v	The chances that the recommended treatment(s) would work	30 (22%)
vi	The chances of developing breast cancer in your breast or chest wall (if your breast was removed) after treatment	61 (44%)
vii	How often you need check-ups	28 (20%)

*Not satisfied due to inadequate information.

Missing data for sexuality item n=12 (8%); breast reconstruction item n=10 (7%); and daughter developing breast cancer n=18 (13%). Missing data for other information items ranged from 0-7 (0-5%).

Women suggested in the open questions in the survey that information about the diagnosis be repeated in follow-up consultations.

“A lot of this information needs to be raised again following surgery as sometimes it is too much to absorb all at once when you are in shock.”

Many women also suggested that more written information about their disease would be helpful.

“It is quite possible some of these things were discussed but being in a state of shock you forget exactly what was said. Written information would be better.”

“Even though my surgeon was very thorough and helpful, I got myself some more information pamphlets so I could refer to them whenever I wanted and familiarize myself more with the medical terms used.”

3.2.3 Treatment decision-making

3.2.3A Decisional conflict

Women were asked to complete Decisional Conflict Scale (DCS) if they felt they had been involved in making the treatment decision-making, that is, if they felt they had *made the decision about your treatment (by yourself or with your doctor)*. Most women [n=114 (79%)] completed the Decisional Conflict Scale. *Table 2.7* outlines the decisional conflict reported by women on the Decisional Conflict Scale.

Overall, approximately half of women expressed high decisional conflict (score >37.5). The total mean Decisional Conflict Scale score for women was 20.5 (SD = 15.6) with 51% expressing high decisional conflict on the uncertainty subscales (Mean=21.2 SD=18.2), 51% on the informed subscale (Mean=24.0 SD=22.0), 45% on the values clarity subscale

(Mean=21.7 SD=17.4), 52% on the support subscale (Mean=21.7 SD=17.5), and 42% on the effective decision subscale (Mean=18.2 SD=14.3).

Table 2.7: Decisional conflict amongst women by the Decisional Conflict Scale (DCS)

	Mean	Standard Deviation	Median	Range	High decisional conflict (>37.5) <i>n (%)</i>
DCS Total Score	20.5	15.6	25	0 - 70.3	54 (47.3%)
<i>i</i> <i>Uncertainty Subscale Score</i>	21.2	18.2	25	0 - 75.0	54 (50.5%)
<i>ii</i> <i>Informed Subscale Score</i>	23.9	22.0	25	0 - 83.3	55 (50.5%)
<i>iii</i> <i>Values Subscale Score</i>	21.7	17.4	25	0 - 75.0	48 (44.9%)
<i>iv</i> <i>Support Subscale Score</i>	21.7	17.5	25	0 - 75.0	56 (52.3%)
<i>v</i> <i>Effective Decision Subscale Score</i>	18.2	14.3	25	0 - 56.3	44 (41.5%)

Missing data on each subscale ranged from 5-8 (4-7%) of women who completed DCS.

3.2.3B Perceived level of involvement in treatment decision-making

Women's perceived level of involvement in treatment decision-making was measured using response options that included *I made the decision using all that I knew and learnt about the treatments; I made the decision but strongly considered the doctor's opinion; the doctor and I made the decision together on an equal basis; the doctor made the decision but strongly considered my opinion; and the doctor made the decision using all that he or she knew about treatments.*

In this item, 30% of women thought that *the doctor made the decision using all that he or she knew about treatments* (see Table 2.8).

Table 2.8: Perceived level of involvement in treatment decision-making amongst women

	<i>n (%)</i>
i The doctor made the decision using all that he or she knew about treatments	42 (30%)
ii The doctor made the decision but strongly considered my opinion	13 (9%)
iii The doctor and I made the decision together on an equal basis	36 (25%)
iv I made the decision but strongly considered the doctor's opinion	39 (27%)
v I made the decision using all that I knew and learnt about the treatments	12 (8%)

Missing data n=2 (1%).

However, 21% of women thought *the doctor made the decision about your treatment* in the previous section of the survey and did not complete the Decisional Conflict Scale (note: women were instructed to complete the Decisional Conflict Scale only if they felt they had been involved in treatment decision-making).

Table 2.9 outlines how women responded to the 'perceived level of involvement in treatment decision-making' item and the first item of the Decisional Conflict Scale. It demonstrates that the results from 'perceived level of involvement in treatment decision-making' item were not consistent with the results from the Decisional Conflict Scale. Fifteen women who reported that *the doctor made the decision* in the 'perceived level of involvement in treatment decision-making' item also completed the Decisional Conflict Scale.

Table 2.9: Women's responses to the 'perceived level of involvement in treatment decision-making' item and the first item of the Decisional Conflict Scale

Deciding about treatment	Decisional Conflict Scale				
	Item 1: decision easy to make				
	<i>strongly agree</i>	<i>agree</i>	<i>neither agree nor disagree</i>	<i>disagree</i>	Total
	<i>n (%)</i>	<i>n (%)</i>	<i>n (%)</i>	<i>n (%)</i>	<i>n</i>
<i>Dr made decision</i>	5 (33%)	7 (47%)	3 (20%)	0 (0%)	15
<i>Dr considered my opinion</i>	7 (58%)	3 (25%)	1 (8%)	1 (8%)	12
<i>Dr and I</i>	15 (47%)	11 (34%)	1 (3%)	5 (16%)	32
<i>I made but considered Dr</i>	15 (38%)	15 (38%)	3 (7%)	6 (15%)	39
<i>I made</i>	3 (27%)	6 (55%)	0 (0%)	2 (18%)	11
Total	45	42	8	14	109

Furthermore, the 'perceived level of involvement in treatment decision-making' item had a low weighted kappa score [$\kappa=0.48$ (95% CL)] and a low observed proportion of agreement (53%) in the test-retest reliability assessment (*see Appendix 2.7*).

Therefore, the 'perceived level of involvement in treatment decision-making' item was removed from the analysis.

3.2.3C Satisfaction with perceived level of involvement in treatment decision-making

Table 2.10 outlines the satisfaction with the perceived level of involvement in treatment decision-making amongst women. Most women reported that they were happy with their level of involvement in treatment decision-making and only 13% of women reported that they would have preferred to have been more involved in deciding about their treatment.

Table 2.10: Satisfaction with the perceived level of involvement in treatment decision-making amongst women

	<i>n (%)</i>
i I would have preferred to have been MORE involved in deciding about my treatment	18 (13%)
ii I am happy with the amount of involvement I had in deciding about my treatment	123 (87%)
iii I would have preferred to be LESS involved in deciding about my treatment	0 (0%)

Missing data n=3 (2%).

3.2.4 Psychological morbidity

3.2.4A Confusion relating to the diagnosis

Table 2.11 outlines the confusion amongst women about aspects of their diagnosis and treatment. The response categories *a little confused* and *very confused* were collapsed to *felt confused*. Most women reported that they felt *a little confused* rather than *very confused* on all confusion items.

Forty-three per cent of women were confused about whether their breast disease can metastasize and 42% were confused about the chances of their breast disease metastasizing or dying from the breast disease after treatment. Approximately one third of women were confused about their type of breast disease. Women were also confused about their ipsilateral and contralateral breast cancer risk with almost half of women feeling confused about the chance of local recurrence after treatment and 44% of women feeling confused about the chances of developing breast cancer in the opposite breast. Women were less confused about why they needed the type of treatment they had compared to other aspects of their diagnosis.

Table 2.11: Confusion amongst women about aspects of their diagnosis and treatment

<i>Diagnosis</i>		confused n (%)
i	The type of breast disease you had	46 (32%)
ii	Whether or not you have the type of breast cancer that can spread to other parts of your body	59 (43%)
iii	The chances of your breast disease spreading to other parts of your body or dying from your breast disease if you did not have treatment	38 (27%)
iv	The chances of developing breast cancer in the opposite breast	60 (44%)
<i>Treatment</i>		
i	Why you needed the type of treatment you had	20 (14%)
ii	The chance of developing breast cancer in the same breast or in the chest wall (if your breast has been removed)	65 (47%)
iii	The chances of your breast disease spreading to other parts of your body or dying from your breast disease after treatment	59 (42%)

Missing data for each item ranged from 2-7 (1-5%).

Women reported in the open questions in the survey that they felt confused about whether they had ‘cancer’ or not.

*“I would have liked medical staff not to ‘beat around the bush’ so much.
Is it or is it not cancer? Just say it!”*

Women’s confusion was compounded by the conflicting descriptions about DCIS amongst health professionals.

“My GP explained to me that I did not have cancer. My specialist explained that I did have early cancer. I was very worried about the two different answers I received. I chose to believe the specialist.”

Some women's confusion was compounded by the conflicting descriptions about DCIS from the same health professional.

"I was told that I had both breast cancer and that I had a pre-cancer, it seemed contradictory and I found this was a bit confusing."

Many women sought additional information about their disease and treatment from the Internet. Some women were confused by the wide variation in how DCIS is described in information on the Internet.

"Most of my information came from the internet and there seems to be differing opinions as to whether DCIS is a cancer or pre-cancer."

3.2.4B Cancer-specific worry

Table 2.12 outlines the worry amongst women relating to their diagnosis. Approximately half of the women worried about their breast disease metastasizing, 43% worried about dying from their disease, 66% worried about developing breast cancer in the same breast or chest wall (if the breast was removed) after treatment, and 75% worried about developing breast cancer in the opposite breast.

Table 2.12: Worry amongst women relating to their diagnosis

Worry relating to the diagnosis	Worried		Did not worry
	<i>Most of the time / Often</i>	<i>Sometimes or occasionally</i>	<i>Rarely or never</i>
	<i>n (%)</i>	<i>n (%)</i>	<i>n (%)</i>
i Your breast disease spreading to other parts of your body	20 (14%)	56 (39%)	67 (47%)
ii Dying from your breast disease	13 (9%)	49 (34%)	81 (57%)
iii Developing breast cancer in the same breast or in the chest wall (if your breast has been removed)	20 (14%)	74 (52%)	48 (34%)
iv Developing breast cancer in the opposite breast	27 (19%)	80 (56%)	35 (25%)

Missing data in each category ranged from 0-2 (0-1.4%).

Women reported in their responses to the open questions in the survey that they worried about whether they would get cancer in the future.

“I know this has affected me more than I like to admit. I don't like talking about my condition even though it is constantly on my mind - not so much what has happened rather what will be in the future.”

Women also worried about their breast disease spreading and dying from their breast disease.

“I couldn't stop thinking about dying and leaving my husband with three young kids.”

“I found the last 12 months worrying. Every little ache & pain was panic stations.”

3.2.4C Anxiety and depression

Table 2.13 outlines mean anxiety and depression scores and number of cases amongst women derived from scores on the HADS. The mean HADS Composite Scale score was 7.89, the mean HADS Anxiety Subscale score was 5.52, and the mean HADS Depression Subscale score was 2.35. Twelve per cent of women were defined as anxious and 2% were defined as depressed by the HADS (score ≥ 11). In addition, 28% of women had scores of ≥ 8 on the HADS Anxiety Subscale and 8% of women had scores of ≥ 8 on the HADS Depression Subscale.

Table 2.13: Anxiety and depression amongst women by the HADS

	Mean	Standard deviation	Median	Range	Cases (≥ 11) <i>n (%)</i>	Doubtful cases (8-10) <i>n (%)</i>	Non-cases (<8) <i>n (%)</i>
<i>HADS Composite Scale</i>	7.89	6.58	6.00	0-28	-	-	-
<i>HADS Anxiety Subscale</i>	5.52	4.34	5.00	0-18	17 (12%)	22 (16%)	98 (72%)
<i>HADS Depression Subscale</i>	2.35	2.85	1.00	0-12	3 (2%)	8 (6%)	127 (92%)

Missing data for HADS Composite Scale: n=7 (5%). Missing data for HADS-A: n=7 (5%). Missing data for HADS-D: n=6 (4%).

Women reported in their responses to the open questions in the survey the emotional difficulty of being diagnosed and treated for DCIS.

“I felt a little depressed, bewildered & eventually angry at why this happened to me.”

“It has been a challenging experience. It continues to be so.”

Women also reported that the diagnosis and treatment for DCIS had negatively impacted their relationships.

“I feel disfigured and tired. The ordeal has affected my relationship with my husband, emotionally and sexually. We don’t seem to be able to talk about it or the future.”

3.2.4D Support from psycho-social health professionals

Table 2.14 outlines the number of women who consulted with a psycho-social health professional (responses not mutually exclusive). Sixty per cent of women had consulted with a psycho-social health professional; 40% with a breast nurse; 42% with a counsellor; and 8% with a psychologist or psychiatrist.

Table 2.14: Number of women who consulted with a psycho-social health professional

	<i>n (%)</i>
i Breast nurse	57 (40%)
ii Counsellor	61 (42%)
iii Psychologist or psychiatrist	12 (8%)
iv Breast nurse or counsellor or psychologist/ psychiatrist	86 (60%)

Responses not mutually exclusive. No missing data

3.3 Aim 2: What factors are associated with poor knowledge about DCIS?

Factors associated with poor knowledge about DCIS, that is, not knowing that DCIS cannot metastasize (responding *False* or *Don't Know* to Knowledge item *If left untreated, DCIS alone cannot spread to other parts of the body*) were initially investigated using univariate analyses followed by logistic regression analysis to adjust for potential confounders. *Section 3.3.1* summarises the factors found to be significantly associated with poor knowledge about DCIS in the univariate analyses. *Section 3.3.2* describes the results from *all* the variables tested in the univariate analyses. *Section 3.3.3* describes the factors found to be associated with poor knowledge about DCIS in the logistic regression analyses.

3.3.1 Factors significantly associated with poor knowledge about DCIS in the univariate analyses

The variables tested in the univariate analyses against not knowing that DCIS cannot metastasize (responding *False* or *Don't Know* to Knowledge item *If left untreated, DCIS alone cannot spread to other parts of the body*) included the following:

- a) Factors that may relate to the causes of poor knowledge including: i) *Participant characteristics*: age (<60yrs vs ≥60yrs); residence (urban vs rural/remote); first language spoken (English vs non-English); education (tertiary vs non- tertiary); employment (employed vs not employed); relationship status (in a relationship vs not in a relationship); and knowing someone close who had breast cancer (yes vs no); ii) *Information*: satisfaction with information about DCIS metastasizing (yes vs no); and receiving information about DCIS metastasizing (yes vs no); and iii) *Consultation with a psycho-social health professional*: consultation with a breast nurse (yes vs no); and consultation with a counsellor (yes vs no).
- b) Factors that may relate to the impact of poor knowledge including: i) *Worry relating to the diagnosis*: worry about DCIS metastasizing (yes vs no); worry about dying from the breast disease (yes vs no); worry about developing breast cancer in the same breast or chest wall (yes vs no); worry about developing breast

cancer in the opposite breast (yes vs no); ii) *Anxiety and depression*: anxiety by HADS (definite case ≥ 11 vs non-case /doubtful case <11 , definite case/ doubtful case ≥ 8 vs non-case <8); iii) *Confusion*: confusion about whether DCIS can metastasize (yes vs no); iv) *Decisional conflict*: Decisional Conflict Scale (high decisional conflict >37.5 vs low decisional conflict ≤ 37.5); and v) *Treatment*: lumpectomy only (yes vs no), mastectomy only (yes vs no); lumpectomy and mastectomy (yes vs no); no surgery after biopsy (yes vs no); radiotherapy (yes vs no).

The variables were tested using chi-square analyses (and Fisher's Exact Test for data cells that had expected counts <5 ; p value <0.05 was considered significant). The Odds Ratio (95% CL) was calculated and provides an estimate for the relationship between poor knowledge and the variables tested in the univariate analyses.

In the univariate analyses, worry relating to the DCIS diagnosis including worry about dying from the breast disease (OR 4.1; $p=0.023$); and worry about developing breast cancer in opposite breast (OR 3.2; $p=0.034$) were found to be significantly associated with not knowing that DCIS cannot metastasize (responding *False* or *Don't Know* to Knowledge item *If left untreated, DCIS alone cannot spread to other parts of the body*). There were no significant associations found between not knowing that DCIS cannot metastasize and other variables in the univariate analyses. *Table 2.15* outlines the significant results from the univariate analyses. *Section 3.3.2* describes the results from *all* the variables tested in the univariate analyses.

Table 2.15: Factors significantly associated with poor knowledge, that is, not knowing that DCIS cannot metastasize (univariate analyses)

			Poor Knowledge n (%)#	Odds Ratio 95% CL	χ^2 (df=1)	p value	Fisher's Exact Test (two-sided)
i	Worry about dying from your breast disease	<i>worry</i>	57 (47%)	4.1	5.141	p=0.023 *	-
		<i>no worry</i>	65 (53%)				
ii	Worry about developing breast cancer in the opposite breast	<i>worry</i>	95 (79%)	3.2	-	-	p=0.034 *
		<i>no worry</i>	26 (21%)				

* Significant $p < 0.05$ Missing values for each item ranged from 0-2 (0-1.4%) p value calculated using Two-sided Fisher's Exact Test for data cells that had expected counts < 5 . # n = number of women who were in this category eg 57 women had poor knowledge and worried about dying from their breast disease and 65 women had poor knowledge and did not worry about dying from their breast disease; % = the number of women who were in this category out of the total number of the women who had poor knowledge eg 47% of women worried about dying from their breast disease who had poor knowledge and 53% of women did not worry about dying from their breast disease who had poor knowledge.

3.3.2 Variables tested in the univariate analyses

Section 3.3.2i-viii describes the results from all the variables tested in the univariate analyses against poor knowledge, that is, not knowing that DCIS cannot metastasize (responding *False* or *Don't Know* to Knowledge item *If left untreated, DCIS alone cannot spread to other parts of the body*).

3.3.2i Relationship between poor knowledge and participant socio-demographic characteristics (univariate analysis)

Table 2.16 outlines the relationship between poor knowledge about whether DCIS can metastasize and participant socio-demographic characteristics. There were no significant associations found between poor knowledge about whether DCIS can metastasize and

participant characteristics such as age, residence, language spoken, education, employment, relationship status; and knowing someone close who had breast cancer.

Table 2.16: Relationship between poor knowledge about whether DCIS can metastasize and participant socio-demographic characteristics (unadjusted)

			Poor Knowledge n (%)	Odds Ratio 95% CL	χ^2 (df=1)	p value	Fisher's Exact Test (two- sided)
i	Age	<i><60yrs</i>	69 (57%)	1.0	0.001	p=0.981	-
		<i>≥60yrs</i>	53 (43%)				
ii	Residence	<i>major city</i>	88 (74%)	0.6	-	-	p=0.400
		<i>regional/ remote</i>	31 (26%)				
iii	First language	<i>English</i>	111 (92%)	1.4	-	-	p=1.000
		<i>other than English</i>	10 (8%)				
iv	Education	<i>tertiary</i>	61 (51%)	0.7	0.381	p=0.537	-
		<i>non-tertiary</i>	59 (49%)				
v	Employment	<i>employed</i>	61 (50%)	1.1	0.067	p=0.796	-
		<i>not employed</i>	60 (50%)				
vi	Relationship status	<i>in a relationship</i>	94 (78%)	2.2	-	-	p=0.525
		<i>not in a relationship</i>	27 (22%)				
vii	Knowing someone close who had breast cancer	<i>knowing someone</i>	69 (57%)	0.7	0.600	p=0.439	-
		<i>not knowing someone</i>	52 (43%)				

Missing values for each item ranged from 6-8 (4-6%); p value calculated using Two-sided Fisher's Exact Test for data cells that had expected counts <5.

3.3.2ii Relationship between poor knowledge and information (univariate analysis)

Table 2.17 outlines the relationship between poor knowledge about whether DCIS can metastasize and information. There were no significant associations found between poor knowledge about whether DCIS can metastasize and satisfaction with or receiving information about whether their breast disease could metastasize.

Table 2.17: Relationship between poor knowledge about whether DCIS can metastasize and information (unadjusted)

			Poor Knowledge n (%)	Odds Ratio 95% CL	χ^2 (df=1)	p value	Fisher's Exact Test (two-sided)
i	Satisfaction with information about whether DCIS could metastasize	<i>satisfied</i>	51 (44%)	1.4	0.482	p=0.487	-
		<i>not satisfied</i>	65 (56%)				
ii	Received information about whether DCIS could metastasize	<i>received</i>	92 (79%)	0.5	-	-	p=0.524
		<i>not received</i>	24 (21%)				

Missing values for each item n=11 (8%); p value calculated using Two-sided Fisher's Exact Test for data cells that had expected counts <5.

3.3.2iii Relationship between poor knowledge and consultation with a psycho-social health professional (univariate analysis)

Table 2.18 outlines the relationship between poor knowledge about whether DCIS can metastasize and consultation with a psycho-social health professional. There were no significant associations found between poor knowledge about whether DCIS can metastasize and consultation with a breast nurse or counsellor.

Table 2.18: Relationship between poor knowledge about whether DCIS can metastasize and consultation with a psycho-social health professional (unadjusted)

			Poor Knowledge n (%)	Odds Ratio 95% CL	χ^2 (df=1)	p value
i	Consultation with a breast nurse	<i>consulted</i>	51 (42%)	0.6	0.952	p=0.329
		<i>not consulted</i>	71 (58%)			
ii	Consultation with a counsellor	<i>consulted</i>	54 (44%)	0.7	0.489	p=0.484
		<i>not consulted</i>	68 (56%)			

No missing data. No tests of association were performed using the variable *consultation with a psychologist/psychiatrist* as n <10%.

3.3.2iv Relationship between poor knowledge and worry relating to the DCIS diagnosis (univariate analysis)

Table 2.19 outlines the relationship between poor knowledge about whether DCIS can metastasize and worry relating to the DCIS diagnosis. Poor knowledge about whether DCIS can metastasize was found to be significantly associated with worry relating to the DCIS diagnosis. Women who had poor knowledge about whether DCIS can metastasize had four times the odds of worrying (rather than not worrying) about dying from their breast disease. Women who had poor knowledge about whether DCIS can metastasize had three times the odds of worrying (rather than not worrying) about developing breast cancer in opposite breast. There were no significant associations found between poor knowledge about whether DCIS can metastasize and worry about developing breast cancer in same breast or about DCIS metastasizing.

Table 2.19: Relationship between poor knowledge about whether DCIS can metastasize and worry relating to the DCIS diagnosis (unadjusted)

			Poor Knowledge n (%)	Odds Ratio 95% CL	χ^2 (df=1)	p value	Fisher's Exact Test (two-sided)
i	Worry about developing breast cancer in the same breast or chest wall	<i>worry</i>	82 (68%)	1.9	1.582	p=0.209	-
		<i>no worry</i>	38 (32%)				
ii	Worry about DCIS metastasizing	<i>worry</i>	68 (56%)	2.3	2.505	p=0.114	-
		<i>no worry</i>	54 (44%)				
iii	Worry about dying from your breast disease	<i>worry</i>	57 (47%)	4.1	5.141	p=0.023 *	-
		<i>no worry</i>	65 (53%)				
iv	Worry about developing breast cancer in the opposite breast	<i>worry</i>	95 (79%)	3.2	-	-	p=0.034 *
		<i>no worry</i>	26 (21%)				

*Significant p <0.05 Missing values for each item range from 0-2 (0-1.4%). p value calculated using Two-sided Fisher's Exact Test for data cells that had expected counts <5.

3.3.2v *Relationship between poor knowledge and anxiety by HADS (univariate analysis)*

Table 2.20 outlines the relationship between poor knowledge about whether DCIS can metastasize and anxiety by HADS (≥ 11 vs <11 ; ≥ 8 vs <8). There were no significant associations found between poor knowledge about whether DCIS can metastasize and anxiety by HADS (≥ 11 vs <11 ; ≥ 8 vs <8).

Table 2.20: Relationship between poor knowledge about whether DCIS can metastasize and anxiety by HADS (≥ 11 vs <11 ; ≥ 8 vs <8) (unadjusted)

			Poor Knowledge n (%)	Odds Ratio 95% CL	χ^2 (df=1)	p value	Fisher's Exact Test (two-sided)
i	Anxiety cases	Case ≥ 11	15 (13%)	2.2	-	-	p=0.692
		Doubtful case/ non-case <11	102 (87%)				
ii	Anxiety	Case/ doubtful case ≥ 8	35 (30%)	1.8	-	-	p=0.556
		Non-case <8	82 (70%)				

Missing values n = 11 (8%). p value calculated using Two-sided Fisher's Exact Test for data cells that had expected counts <5 . No tests of association were performed using the variables *depression by HADS ≥ 11 vs <11 , ≥ 8 vs <8* as number of cases $<10\%$.

3.3.2vi Relationship between poor knowledge and confusion (univariate analysis)

Table 2.21 outlines the relationship between poor knowledge about whether DCIS can metastasize and confusion. Women who were confused had high rates of poor knowledge (n=53, 90%), and women who were not confused also had a similar poor rate of knowledge about the spread of DCIS (n=65, 86%). Therefore, there was no significant association found between poor knowledge about whether DCIS can metastasize and confusion about whether DCIS can metastasize.

Table 2.21: Relationship between poor knowledge about whether DCIS can metastasize and confusion (unadjusted)

		Poor Knowledge n (%)	Odds Ratio 95% CL	χ^2 (df=1)	p value
Confusion about whether DCIS can metastasize	<i>confused</i>	53 (90%)	1.5	0.559	p=0.454
	<i>not confused</i>	65 (86%)			

Missing values n= 9 (6%)

3.3.2vii Relationship between poor knowledge and decisional conflict (univariate analysis)

Table 2.22 outlines the relationship between poor knowledge about whether DCIS can metastasize and high decisional conflict (>37.5).²⁵ There was no significant association found between poor knowledge about whether DCIS can metastasize and high decisional conflict by the Decisional Conflict Scale (DCS).

Table 2.22: Relationship between poor knowledge about whether DCIS can metastasize and high decisional conflict (unadjusted)

		Poor Knowledge n (%)	Odds Ratio 95% CL	χ^2 (df=1)	p value
Decisional conflict	<i>high decisional conflict >37.5</i>	51 (52%)	1.1	0.024	p=0.902
	<i>low decisional conflict ≤37.5</i>	47 (48%)			

Missing values n=3 (2%).

3.3.2viii Relationship between poor knowledge and treatment (univariate analysis)

Table 2.23 outlines knowledge amongst women according to type of surgery reported. All of the women who had both a lumpectomy and a mastectomy and almost all of the women who had a mastectomy only or no surgery (after biopsy) had poor knowledge about whether DCIS can metastasize. Of the women who had a lumpectomy only, 81% had poor knowledge about whether DCIS can metastasize. There appears to be a relationship between poor knowledge about whether DCIS can metastasize and surgery, although not significant. This needs to be further explored in a larger sample which will have a greater power for detecting associations with poor knowledge.

Table 2.23: Knowledge about DCIS according to type of surgery

Surgery		Poor Knowledge n (% who had type of surgery)		Fisher's Exact Test (two-sided)
		<i>Incorrect/don't know</i>	<i>Correct</i>	
i	Lumpectomy only	59 (81%)	14 (19%)	p=0.072
ii	Lumpectomy and mastectomy	18 (100%)	0 (0%)	
iii	Mastectomy only	30 (94%)	2 (6%)	
iv	Neither lumpectomy or mastectomy (No surgery after biopsy)	15 (94%)	1 (6%)	

Missing values n=5 (3%). As none of the women who reported both mastectomy and lumpectomy answered the knowledge question correctly an odds ratio was unable to be calculated.

Table 2.24 outlines the relationship between poor knowledge about whether DCIS can metastasize and radiotherapy. There was no significant association found between poor knowledge about whether DCIS can metastasize and radiotherapy.

Table 2.24: Relationship between poor knowledge about whether DCIS can metastasize and radiotherapy (unadjusted)

		Poor Knowledge n (%)	Odds Ratio 95% CL	χ^2 (df=1)	p value
Radiotherapy	<i>radiotherapy</i>	43 (35%)	2.6	3.516	p=0.061
	<i>no radiotherapy</i>	79 (65%)			

Missing values n=5 (3%).

3.3.3 *Factors associated with poor knowledge about DCIS in the logistic regression analyses*

Factors associated with knowledge about whether DCIS can metastasize were tested using logistic regression analyses to adjust for potential confounders. Variables were included in the logistic regression analysis if they had a p value of 0.25 or less on univariate analyses and backward stepwise regression used to exclude variables with a p values of >0.1 on Wald tests. The goodness-of-fit of the model was tested using the Hosmer-Lemeshow tests. The Odds Ratio (95% CL) was calculated and provides an estimate for the relationship between poor knowledge and the variables tested in the logistic regression analyses.

The variables tested in the logistic regression analyses against not knowing that DCIS cannot metastasize (responding *False* or *Don't Know* to Knowledge item *If left untreated, DCIS alone cannot spread to other parts of the body*) included the factors that may relate to the impact of poor knowledge including:

- i) *Worry relating to the diagnosis*: worry about DCIS metastasizing (yes vs no); worry about dying from your breast disease (yes vs no); worry about developing breast cancer in the same breast or chest wall (yes vs no); and worry about developing breast cancer in the opposite breast (yes vs no).
- ii) *Treatment*: lumpectomy only (yes vs no); mastectomy only (yes vs no); lumpectomy and mastectomy (yes vs no); and radiotherapy (yes vs no).

No other variable was tested in the logistic regression analyses (no other variable had a p value of 0.25 or less on univariate analyses).

In the logistic regression analyses, worry about dying from your breast disease was found to be significantly associated with not knowing that DCIS cannot metastasize (OR 3.9; 95% CI 1.03 - 14.25). Women who did not know that DCIS cannot metastasize had four times the odds of worrying (rather than not worrying) about dying from their breast disease. It

was not possible to estimate whether having a mastectomy predicted poor knowledge as all women who had a mastectomy had poor knowledge about whether DCIS can metastasize. Additionally, women who reported both mastectomy and lumpectomy (13% of the sample) were left out of the model as they caused convergence problems. There were no significant associations found between poor knowledge about whether DCIS can metastasize and other variables tested in the logistic regression analyses. *Table 2.25* outlines the factors found to be associated with poor knowledge about whether DCIS can metastasize in the logistic regression analyses.

Table 2.25: Factors significantly associated with poor knowledge, that is, not knowing that DCIS cannot metastasize (logistic regression analyses)

Parameter	Level	Odds Ratio	Confidence interval (95%)	LR test statistic (df)	p value
Worry about dying from your breast disease	<i>Never worry</i>	Reference			
	<i>Worry</i>	3.9	1.1-14.3	4.03 (1)	0.045 *

*Significant $p < 0.05$ Hosmer-Lemeshow GOF test: $\chi^2 = 0.102$, $df = 2$, $p = 0.9501$ (no evidence that model does not have adequate fit).

3.4 Aim 3: What factors are associated with confusion about DCIS?

Factors associated with confusion about DCIS, that is, confusion about whether DCIS can metastasize (responding *I feel a little or very confused* to Confusion item *Do you feel confused about whether or not you had the type of breast disease that could spread to other parts of your body?*) were initially investigated using univariate analyses followed by logistic regression analysis to adjust for potential confounders. *Section 3.4.1* summarises the factors found to be significantly associated with confusion about whether DCIS can metastasize in the univariate analyses. *Section 3.4.2* describes the results from *all* the variables tested in the univariate analyses. *Section 3.4.3* describes the factors found to be

associated with confusion about whether DCIS can metastasize in the logistic regression analyses.

3.4.1 Factors significantly associated with confusion about DCIS in the univariate analyses

The variables tested in the univariate analyses against confusion about whether DCIS can metastasize (responding *I feel a little or very confused* to Confusion item *Do you feel confused about whether or not you had the type of breast disease that could spread to other parts of your body?*) included the following:

- a) Factors that may relate to the causes of confusion including: i) *Participant characteristics*: age (<60yrs vs ≥60yrs); residence (urban vs rural/remotely); first language spoken (English vs non-English); education (tertiary vs non- tertiary); employment (employed vs not employed); relationship status (in a relationship vs not in a relationship); and knowing someone close who had breast cancer (yes vs no); ii) *Information*: satisfaction with information about DCIS metastasizing (yes vs no); and receiving information about DCIS metastasizing (yes vs no); and iii) *Consultation with a psycho-social health professional*: consultation with a breast nurse (yes vs no); and consultation with a counsellor (yes vs no).
- b) Factors that may relate to the impact of confusion including: i) *Worry relating to the diagnosis*: worry about DCIS metastasizing (yes vs no); worry about dying from the breast disease (yes vs no); worry about developing breast cancer in the same breast or chest wall (yes vs no); worry about developing breast cancer in the opposite breast (yes vs no); ii) *Anxiety and depression*: anxiety by HADS (definite case ≥ 11 vs non-case /doubtful case <11, definite case/ doubtful case ≥ 8 vs non-case <8); iii) *Decisional conflict*: Decisional Conflict Scale (high decisional conflict >37.5 vs low decisional conflict ≤37.5); and iv) *Treatment*: lumpectomy only (yes vs no), mastectomy only (yes vs no); lumpectomy and mastectomy (yes vs no); no surgery after biopsy (yes vs no); radiotherapy (yes vs no).

The variables were tested using chi-square analyses (and Fisher's Exact Test for data cells that had expected counts <5; p value <0.05 was considered significant). The Odds Ratio (95% CL) was calculated and provides an estimate for the relationship between confusion and the variables tested in the univariate analyses.

In the univariate analyses, living in a rural or remote location rather than a city (OR 2.7; p=0.010); dissatisfaction with information about whether DCIS can metastasize (OR 14.1; p<0.001); not receiving information about whether DCIS can metastasize (OR 8.3; p<0.001); worry relating to the DCIS diagnosis [DCIS metastasizing (OR 2.1; p=0.046); dying from your breast disease (OR 2.9; p=0.002); developing breast cancer in same breast (OR 3.8; p=0.001) developing breast cancer in opposite breast (OR 2.4; p=0.044)]; consulting with a breast nurse (OR 2.6; p=0.008); and high decisional conflict > 37.5 (p=0.045); were significantly associated with confusion about whether DCIS can metastasize (responding *I feel a little or very confused* to Confusion item *Do you feel confused about whether or not you had the type of breast disease that could spread to other parts of your body?*).

There were no significant associations found between confusion about whether DCIS can metastasize and other variables in the univariate analyses. *Table 2.26* outlines the significant results from the univariate analyses. *Section 3.4.2* describes the results from *all* the variables tested in the univariate analyses.

Table 2.26: Factors significantly associated with confusion about whether DCIS can metastasize (univariate analyses)

			Confusion n (%)	Odds Ratio 95% CL	χ^2 df=1	p value
i	Residence	<i>major city</i>	35 (60%)	2.7	6.658	p=0.010 *
		<i>regional/ remote</i>	23 (40%)			
ii	Satisfaction with information about whether DCIS could metastasize	<i>satisfied</i>	8 (14%)	14.1	40.702	p<0.001 *
		<i>not satisfied</i>	49 (86%)			
iii	Received information about whether DCIS could metastasize	<i>received</i>	36 (63%)	8.3	18.968	p<0.001 *
		<i>not received</i>	21 (37%)			
iv	Worry about DCIS metastasizing	<i>worry</i>	37 (63%)	2.0	3.983	p=0.046 *
		<i>no worry</i>	22 (37%)			
v	Worry about dying from your breast disease	<i>worry</i>	34 (58%)	2.9	9.316	p=0.002 *
		<i>no worry</i>	25 (42%)			
vi	Worry about developing breast cancer in the same breast or chest wall	<i>worry</i>	48 (81%)	3.8	11.671	p=0.001 *
		<i>no worry</i>	11 (19%)			

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			Confusion n (%)	Odds Ratio 95% CL	χ^2 df=1	p value
vii	Worry about developing breast cancer in the opposite breast	<i>worry</i>	49 (84%)	2.4	4.040	p=0.044 *
		<i>no worry</i>	9 (16%)			
viii	Consultation with a breast nurse	<i>consulted</i>	16 (27%)	2.6	6.975	p=0.008 *
		<i>not consulted</i>	43 (73%)			
ix	Decisional conflict	<i>high decisional conflict > 37.5</i>	26 (58%)	2.2	3.990	p=0.045 *
		<i>low decisional conflict \leq 37.5</i>	19 (42%)			

*Significant p < 0.05 Missing values for each item range from 7-9 (5-6%) p value calculated using Two-sided Fisher's Exact Test for data cells that had expected counts < 5.

3.4.2 Variables tested in the univariate analyses

Section 3.4.2i-vii describes the results from *all* the variables tested in the univariate analyses against confusion about DCIS, that is, confusion about whether DCIS can metastasize (responding *I feel a little or very confused* to Confusion item *Do you feel confused about whether or not you had the type of breast disease that could spread to other parts of your body?*).

3.4.2i *Relationship between confusion and participant socio-demographic characteristics (univariate analysis)*

Table 2.27 outlines the relationship between confusion about whether DCIS can metastasize and participant socio-demographic characteristics. Confusion about whether DCIS can metastasize was found to be associated with women's residence. Women who were confused had three times the odds of living in a rural or remote location rather than a city. There were no significant associations found between confusion about whether DCIS can metastasize and participant characteristics such as age, language spoken, education, employment, relationship status; and knowing someone close who had breast cancer.

Table 2.27: Relationship between confusion about whether DCIS can metastasize and participant socio-demographic characteristics (unadjusted)

			Confusion n (%)	Odds Ratio 95% CL	χ^2 df=1	p value
i	Age	<60yrs	36 (62%)	0.7	1.082	p=0.298
		≥60yrs	22 (38%)			
ii	Residence	major city	35 (60%)	2.7	6.658	p=0.010*
		regional/ remote	23 (40%)			
iii	First language spoken	English	54 (92%)	0.9	0.011	p=0.918
		other than English	5 (8%)			
iv	Education	tertiary	26 (44%)	0.5	2.994	p=0.084
		non-tertiary	33 (56%)			
v	Employment	employed	30 (51%)	1.0	0.010	p=0.922
		not employed	29 (49%)			

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			Confusion n (%)	Odds Ratio 95% CL	χ^2 df=1	p value
vi	Relationship status	<i>in a relationship</i>	49 (83%)	0.6	1.909	p=0.167
		<i>not in a relationship</i>	10 (17%)			
vii	Knowing someone close who had breast cancer	<i>knowing someone</i>	36 (61%)	0.6	1.646	p=0.200
		<i>not knowing someone</i>	23 (39%)			

*Significant p <0.05 Missing values for each item range from 7-9 (5-6%). p value calculated using Two-sided Fisher's Exact Test for data cells that had expected counts <5.

3.4.2ii Relationship between confusion and information (univariate analysis)

Table 2.28 outlines the relationship between confusion about whether DCIS can metastasize and information. Confusion about whether DCIS can metastasize was found to be significantly associated with satisfaction with information about whether DCIS could metastasize. Women who were not satisfied with the information they received about whether their breast disease can metastasize had 14 times the odds of being confused rather than not being confused about whether their breast disease can metastasize compared to women who were satisfied with the information. Confusion about whether DCIS can metastasize was also found to be significantly associated with not receiving information about whether DCIS could metastasize. Women who did not receive information about whether their breast disease can metastasize had eight times the odds of being confused rather than not being confused about whether their breast disease can metastasize compared to women who had received this information.

Table 2.28: Relationship between confusion about whether DCIS can metastasize and information (unadjusted)

			Confusion n (%)	Odds Ratio 95% CL	χ^2 df=1	p value
i	Satisfaction with information about whether DCIS could metastasize	<i>satisfied</i>	8 (14%)	14.1	40.702	p<0.001 *
		<i>not satisfied</i>	49 (86%)			
ii	Received information about whether DCIS could metastasize	<i>received</i>	36 (63%)	8.3	18.968	p<0.001 *
		<i>not received</i>	21 (37%)			

*Significant p <0.05 Missing values for each item n=11 (8%) p value calculated using Two-sided Fisher's Exact Test for data cells that had expected counts <5.

3.4.2iii Relationship between confusion and consultation with a psycho-social health professional (univariate analysis)

Table 2.29 outlines the relationship between poor knowledge about whether DCIS can metastasize and consultation with a psycho-social health professional. Confusion about whether DCIS can metastasize was found to be associated with consulting with a breast nurse. Women who were confused about whether their breast disease can metastasize had three times the odds of not consulting with a breast nurse rather than consulting with a breast nurse. There was no association found between confusion about whether DCIS can metastasize and consultation with a counsellor.

Table 2.29: Relationship between confusion about whether DCIS can metastasize and consultation with a psycho-social health professional (unadjusted)

			Confusion n (%)	Odds Ratio 95% CL	χ^2 df=1	p value
i	Consultation with a breast nurse	<i>consulted</i>	16 (27%)	2.6	6.975	p=0.008 *
		<i>not consulted</i>	43 (73%)			
ii	Consultation with a counsellor	<i>consulted</i>	22 (37%)	1.4	0.951	p=0.330
		<i>not consulted</i>	37 (63%)			

*Significant p <0.05 Missing values for each item n=6 (4%). No tests of association were performed using the variable *consultation with a psychologist/psychiatrist* as number of responses <10%.

3.4.2iv Relationship between confusion and worry relating to the DCIS diagnosis (univariate analysis)

Table 2.30 outlines the relationship between confusion about whether DCIS can metastasize and worry relating to the DCIS diagnosis. Confusion about whether DCIS can metastasize was found to be significantly associated with worry relating to the DCIS diagnosis. Women who were confused about whether their breast disease can metastasize had four times the odds of worrying (rather than not worrying) about developing breast cancer in same breast or chest wall. Women who were confused about whether their breast disease can metastasize had two times the odds of worrying (rather than not worrying) about DCIS metastasising. Women who were confused about whether their breast disease can metastasize had three times the odds of worrying (rather than not worrying) about dying from their breast disease. Women who were confused about whether their breast disease can metastasize had two times the odds of worrying (rather than not worrying) about developing breast cancer in opposite breast.

Table 2.30: Relationship between confusion about whether DCIS can metastasize and worry relating to the DCIS diagnosis (unadjusted)

			Confusion n (%)	Odds Ratio 95% CL	χ^2 df=1	p value
i	Worry about developing breast cancer in the same breast or chest wall	<i>worry</i>	48 (81%)	3.8	11.671	p=0.001 *
		<i>no worry</i>	11 (19%)			
ii	Worry about DCIS metastasizing	<i>worry</i>	37 (63%)	2.0	3.983	p=0.046 *
		<i>no worry</i>	22 (37%)			
iii	Worry about dying from your breast disease	<i>worry</i>	34 (58%)	2.9	9.316	p=0.002 *
		<i>no worry</i>	25 (42%)			
iv	Worry about developing breast cancer in the opposite breast	<i>worry</i>	49 (84%)	2.4	4.040	p=0.044 *
		<i>no worry</i>	9 (16%)			

*Significant $p < 0.05$ Missing values for each item range from 6-8 (4-6%). p value calculated using Two-sided Fisher's Exact Test for data cells that had expected counts < 5 .

3.4.2v Relationship between confusion and anxiety by HADS (univariate analysis)

Table 2.31 outlines the relationship between confusion about whether DCIS can metastasize and anxiety by HADS (≥ 11 vs <11 ; ≥ 8 vs <8). There were no significant associations found between confusion about whether DCIS can metastasize and anxiety by HADS (≥ 11 vs <11 ; ≥ 8 vs <8).

Table 2.31: Relationship between confusion about whether DCIS can metastasize and anxiety by HADS (≥ 11 vs <11 ; ≥ 8 vs <8) (unadjusted)

			Confusion n (%)	Odds Ratio 95% CL	χ^2 df=1	p value
i	Anxiety cases	<i>Case ≥ 11</i>	5 (8%)	0.6	0.573	p=0.449
		<i>Doubtful case/ non-case <11</i>	51 (92%)			
ii	Anxiety	<i>Case/ doubtful case ≥ 8</i>	20 (36%)	1.9	2.847	p=0.092
		<i>Non-case <8</i>	36 (64%)			

Missing values for each item n=12 (8%). No tests of association were performed using the variables depression by HADS ≥ 11 vs <11 , ≥ 8 vs <8 as number of cases $<10\%$.

3.4.2vi Relationship between confusion and decisional conflict (univariate analysis)

Table 2.32 outlines the relationship between confusion about whether DCIS can metastasize and high decisional conflict (>37.5). A significant association was found between confusion about whether DCIS can metastasize and high decisional conflict by the Decisional Conflict Scale (DCS). Women who were confused about whether their breast disease can metastasize had two times the odds of having high decisional conflict rather than low decisional conflict by the Decisional Conflict Scale.

Table 2.32: Relationship between confusion about whether DCIS can metastasize and high decisional conflict (unadjusted)

		Confusion	Odds Ratio	χ^2	p value
		n (%)	95% CL	df=1	
Decisional conflict	<i>high decisional conflict >37.5</i>	26 (58%)	2.2	3.990	p=0.045 *
	<i>low decisional conflict ≤37.5</i>	19 (42%)			

*Significant p <0.05 Missing values n=4 (3%).

3.4.2vii Relationship between confusion and treatment (univariate analysis)

Table 2.33 outlines the confusion about DCIS amongst women according to type of surgery reported. The number of women who were confused and who were not confused in most surgery categories was fairly evenly distributed apart from the lumpectomy and mastectomy group. In this group, one third of women were confused about whether DCIS can metastasize compared to two thirds who were not confused about this aspect. However, the overall differences in the number of women who were confused and not confused were not enough to be statistically significant.

Table 2.33: Confusion about whether DCIS can metastasize amongst women according to type of surgery

Surgery		Confusion about whether DCIS can metastasize	χ^2 df=1	p value
		n (% who had type of surgery)		
		<i>Confused</i>	<i>Not confused</i>	
i	Lumpectomy only	31 (43%)	41 (57%)	
ii	Lumpectomy and mastectomy	6 (33%)	12 (67%)	
iii	Mastectomy only	14 (44%)	18 (56%)	
iv	Neither lumpectomy or mastectomy (No additional surgery after biopsy)	8 (50%)	8 (50%)	
			1.101	0.798
Missing values n=6 (4%)				

The Odds Ratio estimates for surgery versus no surgery are outlined in *Table 2.34*.

Table 2.34: Odds ratio estimates for the relationship between confusion about whether DCIS can metastasize and type of surgery (versus no surgery)

Surgery (vs no additional surgery)	Odds Ratio	95% CL
i Lumpectomy only	1.7	0.5-5.5
ii Lumpectomy and mastectomy	2.7	0.6-11.3
iii Mastectomy only	1.7	0.5-6.1

Table 2.35 outlines the relationship between confusion about whether DCIS can metastasize and radiotherapy. There was no significant association found between confusion about whether DCIS can metastasize and radiotherapy.

Table 2.35: Relationship between confusion about whether DCIS can metastasize and radiotherapy (unadjusted)

		Confusion n (%)	Odds Ratio 95% CL	χ^2 df=1	p value
Radiotherapy	<i>radiotherapy</i>	20 (34%)	1.4	0.885	p=0.347
	<i>no radiotherapy</i>	39 (66%)			

Missing values n=6 (4%).

3.4.3 Factors significantly associated with confusion about DCIS in the logistic regression analyses

Factors associated with confusion about whether DCIS can metastasize were tested using logistic regression analyses to adjust for potential confounders. Variables were included in the logistic regression analysis if they had a p value of 0.25 or less on univariate analyses and backward stepwise regression used to exclude variables with a p values of >0.1 on Wald tests. The goodness-of-fit of the model was tested using the Hosmer-Lemeshow tests. The Odds Ratio (95% CL) was calculated and provides an estimate for the relationship between confusion and the variables tested in the logistic regression analyses.

The variables tested in the logistic regression analyses against confusion about whether DCIS can metastasize (responding *I feel a little or very confused* to Confusion item *Do you feel confused about whether or not you had the type of breast disease that could spread to other parts of your body?*) included the following:

- a) Factors that may relate to the causes of confusion including: i) *Participant characteristics*: residence (urban vs rural/remote); education (tertiary vs non-tertiary); relationship status (in a relationship vs not in a relationship); and knowing someone close who had breast cancer (yes vs no); ii) *Information*: satisfaction with information about DCIS metastasizing (yes vs no); and receiving

information about DCIS metastasizing (yes vs no); and iii) *Consultation with a psycho-social health professional*: consultation with a breast nurse (yes vs no).

- b) Factors that may relate to the impact of confusion including: i) *Worry relating to the diagnosis*: worry about DCIS metastasizing (yes vs no); worry about dying from the breast disease (yes vs no); worry about developing breast cancer in the same breast or chest wall (yes vs no); worry about developing breast cancer in the opposite breast (yes vs no); ii) *Anxiety and depression*: anxiety by HADS (definite case/ doubtful case ≥ 8 vs non-case <8); and iii) *Decisional conflict*: Decisional Conflict Scale (high decisional conflict >37.5 vs low decisional conflict ≤ 37.5).

No other variable was tested in the logistic regression analyses (no other variable had a p value of 0.25 or less on univariate analyses).

In the logistic regression analyses, dissatisfaction with information about whether DCIS can metastasize was significantly associated with confusion about whether DCIS can metastasize (OR 12.5; 95% CI 3.8-40.2). Women who were not satisfied with the information they received about whether their breast disease can metastasize had 12.5 times the odds of being confused about whether their breast disease can metastasize (95% CI) compared to women who were satisfied with the information. Worry about developing breast cancer in the same breast or chest wall (OR 4.1; 95% CI 1.2, 14.2) was also significantly associated with confusion about whether DCIS could metastasize; while worry about DCIS metastasizing was marginally non-significant (OR 3.3; 95% CI 0.92-12.1).

There were no significant associations found between confusion about whether DCIS can metastasize and other variables tested in the logistic regression analyses. *Table 2.36* outlines the factors found to be associated with confusion about whether DCIS can metastasize in the logistic regression analyses.

Table 2.36: Factors significantly associated with confusion about whether DCIS can metastasize (logistic regression analyses)

	Parameter	Level	Odds Ratio	Confidence interval (95%)	LR test statistic (df)	p value
i	Satisfied with information about whether DCIS could metastasize	<i>Satisfied</i>	Reference			
		<i>Not Satisfied</i>	12.5	3.8-40.2	10.2 (1)	0.001
ii	Worry about developing breast cancer in the same breast or chest wall	<i>Never worry</i>	Reference			
		<i>Worry</i>	4.1	1.2-14.2	5.26 (1)	0.022
iii	Worry about DCIS metastasizing	<i>Never worry</i>	Reference			
		<i>Worry</i>	3.3	0.9-12.1	3.53 (1)	0.066

Hosmer-Lemeshow GOF test: $\chi^2=6.43$, df=5, p=0.2664 (no evidence that the model does not have adequate fit). There were no other significant associations found between confusion about whether DCIS can metastasize and other variables.

3.4.4 Summary of the key findings of the study

Table 2.37 summarises the key findings of the study.

Table 2.37: Key findings from the cross-sectional survey of women with DCIS (N=144)

Key findings

1 Knowledge

- i Most women with DCIS described their breast disease as an early stage breast cancer. However, 59% of women also described their breast disease as a non-invasive breast cancer and 44% as a pre-cancer.
- ii Sixty per cent of women thought that DCIS could metastasize, 27% did not know, and only 12% knew that DCIS cannot metastasize.
- iii Poor knowledge about DCIS was found to be significantly associated with worry about dying of the breast disease. Women who did not know that DCIS cannot metastasize had four times the odds of worrying about dying from their breast disease (logistic regression analysis).
- iv Only 19% of women with DCIS knew that not *all* women with DCIS would develop invasive breast cancer if left untreated.
- v Most women understood that the aim of treating DCIS is to remove the DCIS and prevent it from developing into the type of breast cancer that can spread to other parts of the body.

2 Information needs

- i Approximately half of women with DCIS would have like more information about whether their breast disease could metastasize, one third would have liked more information about the type of breast disease they had, 44% would have liked more information about the chances of local recurrence after treatment, and one third would have liked more information about the chances of their breast disease metastasizing or dying from their breast disease if they did or did not have treatment.
- ii Dissatisfaction with information was found to be significantly associated with confusion about whether DCIS can metastasize. Women with DCIS who were not satisfied with the information they received about whether their breast disease can metastasize had 12.5 times the odds of being confused about whether their breast disease can metastasize compared to women who were satisfied with the information (logistic regression analysis).
- iii Methods suggested by women with DCIS to increase their understanding and recall about their diagnosis include: repeating information about the diagnosis in follow-up consultations; and more written information about their disease.

continued next page

Key findings

3 Treatment decision-making

- i Approximately half of women with DCIS expressed high decisional conflict (score >37.5) in treatment decision-making as measured by the Decisional Conflict Scale (DCS).
- ii Most women reported that they were happy with their level of involvement in treatment decision-making.

4 Psychological morbidity

- i Forty-three per cent of women were confused about whether their breast disease can metastasize and 42% were confused about the chances of their breast disease metastasizing or dying from the breast disease after treatment. Approximately one third of women were confused about their type of breast disease.
 - ii Women with DCIS reported that they felt confused about whether they had ‘cancer’ or not.
 - iii Women’s confusion was compounded by the different terms used by health professionals to describe their diagnosis, and by the different terms used in the written information about their diagnosis, including information from the Internet.
 - iv Approximately half of women with DCIS worried about their breast disease metastasizing, 43% worried about dying from their disease, 66% worried about developing breast cancer in the same breast or chest wall (if the breast was removed) after treatment, and 75% worried about developing breast cancer in the opposite breast.
 - v Worry about dying of the breast disease was found to be significantly associated with poor knowledge about DCIS. Women who did not know that DCIS cannot metastasize had four times the odds of worrying about dying from their breast disease compared to women who had good knowledge of DCIS (logistic regression analysis).
 - vi Overall 60% of women with DCIS had consulted with a psycho-social health professional including: 40% with a breast nurse, 42% with a counsellor, and 8% with a psychologist or psychiatrist.
 - vii Twelve per cent of women were defined as anxious and 2% were defined as depressed by the HADS (score ≥ 11).
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4 Discussion

As demonstrated in the review described in *Chapter 1*, this study is one of a small number of studies that examines the experiences of women diagnosed with DCIS. This study provides a greater understanding of the needs of women with DCIS essential for developing guidelines and interventions for improving care. There are five important findings from this study.

First, this study found that many women did not understand how DCIS differs from invasive breast cancer with only 12% of women knowing that DCIS cannot metastasize. The study also found that a high proportion of women were confused about aspects of their diagnosis with 43% of women being confused about whether their breast disease can metastasize, 42% being confused about the chances of their breast disease metastasizing or dying from the breast disease after treatment, and approximately one third of women being confused about their type of breast disease. Women's confusion was compounded by the different terms used to describe DCIS by the various health professionals, and even from the same health professional, such as 'early breast cancer', 'pre-cancer' and 'non-invasive breast cancer', and the different terms used to describe DCIS in written information (including information from the Internet). Studies with women with DCIS have found that women's description of their breast disease varies greatly.^{9,10,12,13} Similarly, research with doctors has found that consistent terms are not used to describe DCIS to patients.³³

Second, this study found that women with DCIS have poor knowledge about the central uncertainty surrounding DCIS with only 19% of women knowing that not *all* women with DCIS would develop invasive breast cancer if untreated. None of the previous quantitative studies have examined women's knowledge of the uncertainty about DCIS progression to invasive breast cancer. The shift towards informed consent and shared decision-making, means that doctors must effectively communicate medically relevant knowledge including the risks and uncertainties.^{34,35,36} In a recent qualitative study, most women wanted more honest information about DCIS including information about the uncertainties relating to DCIS.⁹ However, currently there are no clear best practices for presenting uncertainty to

patients.³⁷ Research suggests that doctors fear that communicating uncertainty to patients may undermine patient trust,³⁸ that patients will perceive them as inadequate or ineffective,³⁹ and that it will increase patients' anxiety.⁴⁰ However, there is little empirical evidence about the impact on patients of communicating uncertainty. In relation to DCIS, perhaps doctors also fear that disclosing the uncertainty about the natural history of DCIS may affect women's willingness to have treatment. Further research is needed to assess women's and doctors' responses to the uncertainty involved in DCIS, and to develop effective strategies for communicating this uncertainty and helping women manage the impact of the uncertainty.

Third, this study found that women with DCIS want more information about their diagnosis and prognosis. Meeting patients' information needs has been shown to increase understanding,⁴¹ and improve psychological adjustment and perceived quality of life.^{42,43,44} The present study found that women with DCIS want more information about their type of breast disease, whether their breast disease can metastasize, the chances of dying from the breast disease if they did or did not have treatment, and the chances of local recurrence after treatment. None of the previous quantitative studies have examined women's satisfaction with information about different aspects of their diagnosis and prognosis. Furthermore, the logistic regression analysis in the present study found that dissatisfaction with information was significantly associated with confusion about whether DCIS can metastasize. Women with DCIS who were not satisfied with the information they received about whether their breast disease can metastasize had 12.5 times the odds of being confused about whether their breast disease can metastasize compared to women who were satisfied with the information. Given the complexities involved in DCIS, good communication is essential to facilitate understanding of the information.⁴⁵ Simple strategies such as assessing patients' understanding during the consultation, repeating and summarising key information, and actively encouraging questions can improve understanding of the information.^{45,46}

The National Breast Cancer Centre Psychosocial Clinical Practice Guidelines for women with breast cancer⁴⁷ recommend that women receive information and support from a

specialist breast nurse. Research has shown that discussions with a specialist breast nurse increases understanding and recall of information for women with invasive breast cancer.^{48,49} In the univariate analysis in the present study, confusion about whether DCIS can metastasize was found to be significantly associated with consulting with a breast nurse. Women who were confused about whether their breast disease could metastasize had three times the odds of *not* consulting with a breast nurse. Further research is needed to examine the potential benefits for women with DCIS of receiving information and support from a specialist breast nurse.

Fourth, this study found that approximately half of the women in the survey experienced high decision conflict in treatment decision-making. Qualitative studies suggest that women with DCIS experience difficulty in treatment decision-making.^{9,10} However, none of the previous quantitative studies have examined decisional conflict in women with DCIS. High decisional conflict has been shown to result in delayed decision-making and feeling emotionally distressed by the decision.¹⁶ In the univariate analysis in the present study, high decisional conflict was significantly associated with confusion about whether DCIS could metastasize. Better communication about how DCIS differs from invasive breast cancer may reduce decisional conflict in women with DCIS. Decisional conflict may also be lowered by involving patients in treatment decision-making⁵⁰ and with interventions that support decision-making by informing patients about options, benefits, risks, and side effects and that clarify personal values related to treatment outcomes.⁵¹

Fifth, this study found that a high proportion of women experienced ‘cancer-specific worry’. Using DCIS-specific worry items developed by the author, this study found that approximately half of women worried about their breast disease metastasizing, 43% worried about dying from their breast disease, and 66% worried about local breast cancer recurrence after treatment. Furthermore, the logistic regression analysis found that worry about dying of the breast disease was significantly associated with poor knowledge about DCIS. Women who did not know that DCIS cannot metastasize had four times the odds of worrying about dying from their breast disease compared to women who had good knowledge of DCIS. Better communication about how DCIS differs from invasive breast

cancer is essential to alleviating the cancer-specific worry in women with DCIS. Good communication is also needed to elicit and respond to the emotional concerns or ‘cues’ and cancer-specific worries of women and refer to support services when needed.^{52,53} Further research is needed to identify the subtypes of women with DCIS who may be in most need of support.¹⁸

4.1 Limitations of the study

This study was limited by the small sample size and low statistical power. Further research with a larger sample size will have greater power to detect factors associated with less knowledge and greater confusion about DCIS.

Most women in the study spoke English as their first language. Lack of understanding about DCIS may be even more pronounced in women from culturally and linguistically diverse (CALD) backgrounds. For example, Latina US women have been found to have poorer knowledge about DCIS and more psychological distress than White women¹³ and Chinese Canadian women with DCIS have also been found to have poor knowledge about DCIS.⁵⁴ Further research is needed to assess the understanding and impact of a diagnosis of DCIS among women from CALD backgrounds including Australian Aboriginal women.

This study used a cross-sectional design and was therefore limited to assessing outcomes at a particular point in time, that is, during the first year after diagnosis. The study was also not able to assess changes over time. The associations demonstrated in this study are hypothesis generating only. Randomised controlled clinical trials would be able to establish causal links between associations.⁵⁵

Although this study benefits from the inclusion of survey items developed specifically for women with DCIS, development of knowledge, confusion and DCIS-specific worry scales with further validation would be useful given the paucity of rigorously tested psychometric instruments specific to the DCIS diagnosis.

4.2 Conclusions

This study found misunderstanding and confusion amongst women diagnosed with DCIS. Women's confusion was associated with inadequate information about DCIS and compounded by conflicting terms used to describe DCIS. The study also found that women who had poor knowledge about DCIS were more likely to worry about dying from DCIS. Recommendations about how best to communicate a diagnosis of DCIS are needed to guide health professionals to promote better understanding about DCIS and improve the well-being of women with DCIS.

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Chapter 3

Key communication elements for effectively communicating with women diagnosed with ductal carcinoma in situ (DCIS)

Introduction

Chapter 1 and *Chapter 2* demonstrate that there is confusion and misunderstanding among women diagnosed with DCIS about how their diagnosis differs from invasive breast cancer and a desire for more information about key aspects of their diagnosis and treatment. These chapters show that women diagnosed with DCIS experience unnecessary distress due to their lack of understanding about their diagnosis. Improved doctor-patient communication about DCIS is likely to increase women's understanding about DCIS and reduce women's distress.

Although there are currently evidence-based recommendations for clinicians about how to effectively communicate with women diagnosed with invasive breast cancer such as the National Breast and Ovarian Cancer Centre *Psychosocial Clinical Practice Guidelines: Information, Support and Counselling for Women with Breast Cancer*¹ there are no comprehensive evidence-based recommendations that outline for clinicians how to effectively communicate with women diagnosed with DCIS. While some of the recommendations developed for women with invasive breast cancer are also relevant to women with DCIS, there are additional communication challenges specific to DCIS arising from the fact that DCIS is not an invasive cancer and that the diagnosis, prognosis and treatment of DCIS involve much uncertainty.

This chapter therefore describes the first stage of development of recommendations for clinicians about communicating with women diagnosed with DCIS. The recommendations are referred to in this thesis as *Key communication elements for effectively communicating with women diagnosed with ductal carcinoma in situ (DCIS)* or *Key Communication Elements (DCIS)*. The *Key Communication Elements (DCIS)* consist of (a) elements drawn from existing established recommendations for general communication with patients and, in particular, communication with women with invasive breast cancer; and (b) new elements designed to address the particular needs of women with DCIS.

The *Key Communication Elements (DCIS)* are based on a systematic review of the experiences of women diagnosed with DCIS described in *Chapter 1*, the cross-sectional study of Australian women with DCIS described in *Chapter 2*, and the literature related to doctor-patient communication as described in *Part 1* of this chapter. It is acknowledged that the evidence concerning the experiences of women with DCIS is limited to descriptive studies (including observational studies and qualitative studies) and that there is currently no evidence of the effectiveness of the proposed recommendations with women with DCIS. Therefore, the *Key Communication Elements (DCIS)* cannot yet be considered the ‘gold standard’ for communication about DCIS.

The *Key Communication Elements (DCIS)* aim to outline for clinicians how to effectively communicate with women diagnosed with DCIS in a way that promotes understanding about DCIS; addresses the uncertainties related to DCIS; provides hope and reassurance; promotes understanding about treatment options; promotes shared decision-making; and offers emotional support.

This chapter consists of 3 parts.

Part 1 describes a review of the communication literature. The first section of this review (**1.1**) is a detailed description of the literature about communicating uncertainty. This literature is described in more detail than other aspects of the communication literature because communicating about uncertainty is particularly relevant to DCIS given the various diagnostic, prognostic and treatment uncertainties surrounding DCIS. Furthermore, the uncertainty communication literature is diverse, has largely not been synthesised and has been addressed only superficially in previous communication guidelines. The second part of this review (**1.2**) describes other aspects of the communication literature. This literature is briefly described as it has already been summarised in communication guidelines for communicating with cancer patients^{1,2} and in communication skills training programs to help health professionals to communicate better with patients.³ This section of the review considers three aspects of the communication literature in particular: general communication skills; patient information needs; and shared decision-making.

Part 2 describes the development of the *Key Communication Elements (DCIS)* and how each recommendation is derived from the evidence.

Part 3 describes an initial pilot test of the *Key Communication Elements (DCIS)* with a small sample of clinicians and senior health researchers.

Part 1 Descriptive review of the communication literature

The communication literature was searched with the aim of identifying key papers in each of the areas of interest, with a particular focus on communicating with cancer patients. There was no intention to systematically search and review all papers in the areas of interest. Examples of key terms used include: *patient-physician interaction; doctor patient communication; patient-physician communication; clinical practice; education; communication skill; communication skills training; patient participation; patient education; patient-centred care; patient information; satisfaction; breaking bad news; uncertainty; physician uncertainty; illness uncertainty; expressions of uncertainty; uncertainty in patient care; risk communication; fear of cancer recurrence; evidence-based medicine; medical evidence; medical education; treatment decision making; and shared decision making.*

1.1 Review of the uncertainty communication literature

Recently, Epstein and Street proposed a framework of the goals of medical communication and distinguished ‘managing uncertainty’ as one of the functions of doctor-patient communication.^{4,5} However, the task of ‘managing uncertainty’ for doctors is complex given the numerous sources of uncertainty in medical care.^{6,7,8,9,10,11,12,13,14,15}

For the purpose of the review ‘uncertainty communication’ is distinguished from ‘risk communication’. Risk communication involves the communication of probabilities related

to, for example, the benefits and harms of medical interventions.^{7,16,17,18} However, some of the *uncertainties* associated with risk communication are mentioned briefly in the review.

In this review, three major sources of uncertainty in medical care have been differentiated including: *uncertainty relating to the medical evidence*; *uncertainty relating to the individual doctor's lack of knowledge*; and *uncertainty relating to the experience of illness, in particular the experience of cancer*. **Part 1.1.1** describes the literature concerning uncertainty relating to the medical evidence and the individual doctor's lack of knowledge. **Part 1.1.2** describes the literature concerning uncertainty relating to the experience of illness.

1.1.1 Uncertainty relating to the medical evidence and the individual doctor's lack of knowledge

1.1.1A Sources of uncertainty relating to the medical evidence

Evidence-based medicine aims to reduce uncertainty by using the best and most recent scientific evidence in medical decision-making.¹⁹ However, the practice of evidence-based medicine has revealed a multitude of uncertainties that affect the diagnosis, prognosis and treatment of patients.^{7,20,21,22,23,24} Important causes of uncertainty relating to the medical evidence include the uncertainty that occurs when the evidence is unknown or unknowable;^{7,25} the uncertainty involved in applying the evidence to the individual patient;^{26,27,28} the uncertainty involved in generalising research findings and conclusions from a study conducted on a sample population to other populations or subpopulations (affected by factors such as the sample size, sample characteristics, study settings, timing of assessment(s), and the outcome measures assessed);^{24,25,29,30,31,32} the uncertainty involved in transferring findings from qualitative studies beyond the context in which the study was conducted (affected by factors such as the sampling strategy, the sample characteristics, and the study settings);^{33,34} the uncertainty involved in the reliability, validity and quality of the evidence (affected by factors such as the psychometric rigor of the measures used, and whether the study investigators used methods to minimise bias in study design and in the

conduct of a study);^{24,25,29,35} and the uncertainty involved in statistical measurements such as the margin of error of a measurement and whether confidence intervals capture all of the uncertainty around estimates.³⁶

Evidence-based clinical practice guidelines provide a synthesis of the evidence to assist doctors in medical decision-making. However, there are a range of uncertainties involved in evidence-based clinical practice guidelines. Apart from the uncertainties in the primary studies³⁷ and the uncertainty that occurs when not all the evidence is known or knowable,²⁵ there is also uncertainty involved in synthesising quantitative evidence from different patient populations,⁷ synthesising qualitative evidence with different theoretical frameworks and contexts,³⁸ and synthesising qualitative *and* quantitative evidence. Furthermore, uncertainty is involved in the quality of the methods used to identify and evaluate the evidence.²¹

1.1.1B Sources of uncertainty relating to the individual doctor's lack of knowledge

Another major source of uncertainty in medical care relates to the individual doctor's lack of knowledge.^{24,39} Lack of knowledge may arise from inadequate time to search for and critically appraise the literature, limited access to the evidence, the costs of accessing evidence, or inadequate critical appraisal skills.^{25,40,41,42} Inadequate critical appraisal skills may be due to inadequate training or a lack of perceived need to acquire the critical appraisal skills.^{40,43,44}

Evidence-based medicine also involves the application of the doctor's clinical expertise and knowledge of the patient's values and goals in decision-making.^{21,45,46,47} Therefore, the individual doctor's lack of knowledge may also be due to inadequate clinical knowledge and experience, for example, the doctor may be uncertain of the diagnosis or its causes, or how to manage the patient, or how to perform a specific skill or task.^{48,49,50} The individual doctor's lack of knowledge may also be due to inadequate knowledge about the patient's values and goals. Poor knowledge about the patient's values and goals may be caused by poor communication skills or a paternalistic decision-making style.^{51,52,53}

1.1.1C Doctors' tolerance of uncertainty

There is a growing awareness among doctors about uncertainty in medical care.^{20,25,40} The empirical evidence about doctors' tolerance of uncertainty in medical care is limited. There is some evidence about doctors' tolerance of the uncertainty relating to the individual doctor's lack of knowledge, medical care overall, and uncertainty in general.^{54,55,56,57} The evidence suggests that doctors' tolerance of uncertainty may depend on personal characteristics and values and may affect the extent to which doctors disclose uncertainty to patients. However, little is known about doctors' tolerance of the uncertainties relating to the medical evidence.

The Physician Response to Uncertainty Scale (PRU) was developed to assess doctors' tolerance of uncertainty related to the individual doctor's lack of knowledge, for example, "I prefer patients not know when I am uncertain of what treatments to use"; uncertainty in general, for example, "I don't like to work on a problem unless there is a possibility of getting a clear-cut and unambiguous answer"; and uncertainty in medical care overall, for example, "*I find the uncertainty involved in patient care disconcerting*".⁵⁸ The refined scale also measured 'anxiety due to uncertainty', 'concern about bad outcome', 'reluctance to disclose uncertainty' and 'reluctance to disclose mistakes to physicians'.⁵⁹ Greater doctor intolerance of uncertainty as measured by the PRU scale (or adaptations of the scale) have been shown to increase the use of diagnostic tests,⁵⁵ increase patient charges,⁵⁶ and affect the doctor's choice of medical specialty with anesthesiologists, orthopedists, and urologists demonstrating greater intolerance of uncertainty than primary care physicians such as general practitioners.⁵⁷

1.1.1D Doctors' communication of uncertainty

Little is known about how and to what extent doctors communicate the uncertainties related to the medical evidence to patients. Griffiths *et al* in a qualitative study of clinical consultations categorised doctor-patient communication about the uncertainty in the medical evidence, particularly the uncertainty in applying the evidence to individual patients, into three groups: *one*, focusing on certainty for now and this test, with slippage into general reassurance; *two*, giving a coherent account of the medical evidence for risks and benefits, but blurring the uncertainty inherent in the evidence and giving an impression of certainty; and *three*, acknowledging the inherent uncertainty of the medical evidence and negotiating a provisional decision.⁶⁰

There is also a lack of empirical research about how and to what extent doctors communicate the uncertainties related to their lack of knowledge in real consultations with patients. Gordon *et al* measured doctors' expressions of uncertainty (for example, "I don't know") during patient consultations and found that doctors who made more uncertainty expressions also used more positive talk and partnership building, and gave more information to patients.⁵⁴ The study also found that doctors expressed more uncertainty to patients with greater education, patients with greater desire for information, and patients who asked more questions.

1.1.1E Impact of communicating about uncertainty on patients

Doctors may be reluctant to disclose uncertainty to patients due to fear that it may undermine patient trust, that patients will perceive them as inadequate or ineffective, or that it will increase patients' anxiety.^{39,57} However, there is little empirical evidence about patients' perceptions of whether doctors should disclose uncertainty and the impact of disclosing uncertainty on patients. Gordon *et al* found that doctors' expressions of uncertainty (for example, "I don't know") were associated with greater patient satisfaction, but were not independent of other doctor verbal behaviours such as positive talk.⁵⁴ In contrast, Ogden *et al* found that patients viewed uncertainty statements such as "I don't

know”, “Let’s see what happens”, “I need time to find out more”, “I think it might be...” as potentially damaging to their confidence in their doctor.⁴⁸ However, patients in the Ogden *et al* study thought that being referred to a book or the Internet or their doctor asking the advice of a hospital doctor were benign or even beneficial activities. The impact of expressions of uncertainty were found to vary according to patients’ characteristics and the length of time the patient had known the doctor with older, more educated patients who knew their doctor better feeling more confident about verbal and behavioural expressions of uncertainty than younger, less educated patients.

Similarly, two studies concerning doctors’ expressions of uncertainty that involved simulated medical consultations found that expressions of uncertainty decreased patient confidence.^{61,62} Blanch *et al* in a study involving patient satisfaction ratings of simulated videotaped consultations with medical students found that greater expressions of uncertainty were associated with patients perceiving that the medical students lacked confidence, competence, communication skills, and likeability.⁶² In addition, male medical students who had greater expressions of uncertainty were considered more incompetent than female medical students who had a similar level of uncertainty expression. Johnson *et al* in an older study involving patient satisfaction ratings of simulated videotaped consultations with doctors who discussed antibiotic prophylaxis for a heart murmur found that patients were most satisfied when the doctor disclosed no uncertainty and least satisfied when the doctor disclosed but did not discuss uncertainty or consulted a resource in the patient’s presence.⁶¹ Patients’ dissatisfaction with disclosure of uncertainty was also found to be greater in patients who expected doctors to “always know the answers”.

The impact on patients of communicating about the uncertainties related to the medical evidence has not been assessed in the literature. Han *et al* assessed laypersons’ perceptions of the uncertainty regarding cancer risk estimates and found that uncertainty increased anxiety in some individuals and not others.³⁶ The study also found that differences in responses were due to differences among participants in their level of optimism or other motivations that reduced their feelings of vulnerability and personal lack of control.

Although the empirical evidence about the benefits for patients of doctors' expressions of uncertainty is sparse, many ethicists and researchers believe that the expression of uncertainty in medical consultations could have many potential positive outcomes for both the doctor and patient including promoting realistic patient expectations about medical care and its limitations,^{27,63,64} promoting realistic patient expectations about doctor certainty and infallibility and decreasing the burden on doctors,^{65,66} increasing acceptance that the doctor is the only source of information for patients,²⁰ ensuring a greater level of shared decision-making with a more informed decision-making process,^{6,67,68} decreasing malpractice claims due to incomplete disclosure,^{20,66} allowing greater communication about patients' and doctors' goals and values,²⁰ allowing patients to deepen their understanding while building a supportive and trusting relationship with their doctors,^{66,69} and increasing patient satisfaction.^{23,39}

1.1.1F Strategies for communicating about uncertainty with patients

Few studies have discussed or evaluated strategies for doctors about how to communicate the uncertainties related to the medical evidence and the individual doctor's lack of knowledge. Hewson *et al* described steps for 'strategic management' of uncertain and complex medical problems, including acknowledging and discussing uncertainty; keeping diagnostic options open by making provisional diagnoses; and planning for contingencies by providing appropriate if/then statements concerning situations requiring further action.⁷⁰ Other researchers have also discussed the potential benefits of making provisional diagnoses and decisions.^{49,60} Griffiths *et al* suggest that doctors use provisional decisions that allow for changing priorities and circumstances over time, to avoid slippage into general reassurance from a particular test result, and to avoid the creation of the myth of certainty.

Patient decision aids may assist doctors to communicate about some types of uncertainty relating to the medical evidence.¹⁶ Elwyn *et al* developed a quality criteria framework for patient decision aids which outlines that information should be included in patient decision

aids about the quality and strength of the evidence and the statistical uncertainties, for example, by giving a range of probabilities or by using phrases such as ‘our best guess is’.⁷¹

Further research is needed to develop and evaluate strategies for effective communication about uncertainty related to the medical evidence and the individual doctor’s lack of knowledge including helping doctors tailor uncertainty information to the individual patient and helping patients cope with these sources of uncertainty.

1.1.2 *Uncertainty in illness*

1.1.2A *Theory of uncertainty in illness*

Another major source of uncertainty relates to the patient’s experience of illness.^{6,8,11,12,72,73,74,75,76,77} Mishel’s Uncertainty in Illness Theory (UIT) is the most frequently used approach to uncertainty in illness and provides a framework for many interventions to improve psychological and behavioural outcomes under conditions of uncertainty.^{78,79,80,81,82} According to Mishel’s Uncertainty in Illness Theory, uncertainty is generated when a person perceives aspects of the illness and treatment as inconsistent, random, complex and unpredictable.¹¹ However, uncertainty is in essence a neutral cognitive state which can be appraised as an opportunity or a danger.^{8,11} If uncertainty is appraised as a danger it can lead to psychological distress such as fear, anxiety, sadness, helplessness, anger, and a loss of sense of control.^{73,79,83,84,85} Uncertainty may be appraised as a natural component of reality and as an opportunity or a source of hope.^{12,86} ‘Positive reappraisal’ or ‘cognitive reframing’ of uncertainty is used as a strategy to help patients cope with uncertainty in many uncertainty management interventions.^{78,80-82, 87}

1.1.2B *Sources of uncertainty in illness*

Among women with invasive breast cancer, an important source of uncertainty relates to the possibility of recurrence and the changes recurrence will bring in the woman’s life.^{73,74,80,87} Uncertainty is increased by an inability to judge the meaning and significance

of new or on-going symptoms and whether these symptoms indicate recurrence of the cancer.^{73,80} Thoughts of recurrence in women with early breast cancer have also been shown to be triggered by hearing cancer-related media stories, hearing about someone else's cancer or worsening disease, attending annual mammograms and check-ups, and experiencing sights or smells associated with treatment.^{73,74,80,87} Triggers of thoughts of recurrence in women with early breast cancer have been targeted in uncertainty management interventions.^{80,87} Other sources of uncertainty for women with early breast cancer are: knowing why they developed invasive breast cancer; what treatment side effects they will experience and how they will manage them; how they will cope with the changes associated with the illness and treatment; how their family will cope with their illness and whether they will receive adequate support from them; and whether they will receive good care and advice from their health care providers.^{6,15,72,80,87}

1.1.2C Assessment of uncertainty in illness

Patients' experiences of uncertainty in illness have been assessed using qualitative^{6,74} and quantitative methodologies.^{84,88} Two instruments have been developed to measure uncertainty in illness, the Mishel Uncertainty in Illness Scale (MUIS)⁸⁸ and the Uncertainty Stress Scale (USS).⁸⁴ The MUIS assesses ambiguity, complexity, lack of information and unpredictability concerning illness, diagnosis, and treatment, with different versions for different patient populations such as cancer patients. It includes items such as "*I don't know if my cancer will ever come back*" and "*I have been told different things about what my treatment side effects mean*". The USS measures uncertainty in illness, and the stress, threat, and positive feelings generated from the uncertain state.

Fear of cancer recurrence is recognised as a very common concern in cancer survivors that may persist long after the cancer diagnosis with several instruments being developed to evaluate this concern.^{85,89,90,91} The concepts of 'fear of cancer recurrence' and 'uncertainty about cancer recurrence' have not been clearly distinguished in the literature. Uncertainty management interventions usually evaluate coping strategies for 'fear of cancer recurrence'.^{80,81}

1.1.2D Patients' tolerance of uncertainty

Patients' interpretations and responses to uncertainty may depend on personal characteristics and values including personal perceptions of control over events;⁷⁹ belief in God or a higher power;⁸⁶ the individual's sense of purpose and meaning;⁹² patients' education, cognitive capacity, and problem-solving attitude;^{11,93} and patients' optimism, resilience, and humour.^{11,92}

1.1.2E Helping patients manage uncertainty

Helping patients manage uncertainty involves both reducing uncertainty and helping patients cope with uncertainty.^{8,80,86,94} Uncertainty can be reduced by providing patients with generalised and tailored written and verbal information about what is known about their illness and treatment including how to manage treatment side effects.^{72,81,86,94,95} In addition, the patient's social support system including the patient's partner, family and friends can help the patient manage uncertainty by assisting the patient to acquire and interpret information, maintain a positive attitude, and by providing emotional support.^{72,86,95}

A number of uncertainty management interventions for women with early breast cancer^{79,80,87,95} and men with prostate cancer^{72,78,81,82} have found that, in addition to providing information to patients, other strategies that are effective in helping patients manage uncertainty include: cognitive-behavioural strategies such as 'positive reappraisal' or 'cognitive reframing' of the uncertainty including looking at the situation from a positive perspective, for example, "*this diagnosis does not signal death*"; relaxation and calming self-talk during situations that trigger the uncertainty of recurrence; communication skills training with patients to improve their assertiveness and communication with doctors; and training patients in problem-solving skills including identifying and formulating specific questions based on their concerns.

Although uncertainty management interventions have been successful, little is known about the strategies doctors can use during consultations to help patients manage the uncertainty associated with the experience of illness. It is clear that patients need information to help them manage uncertainty.^{79,80} However, it is not clear whether cognitive-behavioural strategies and extensive psychosocial support for uncertainty should be provided during routine clinical care or if specialised psychological interventions are necessary.⁴ Further research is needed to develop and evaluate strategies to help patients manage the uncertainty associated with the experience of illness that are feasible for doctors to use with patients during the consultation.

1.2 Review of other relevant areas of the communication literature

Three other areas of relevance to communicating with women with DCIS are briefly discussed below: i) general communication skills; ii) patient information needs; and iii) shared decision-making. This literature is briefly described as it has already been summarised in communication guidelines for communicating with cancer patients^{1,2} and in communication skills training programs to help health professionals to communicate better with patients.³

1.2.1 General communication skills

A central objective of many communication skills training modules^{3,96,97,98,99,100,101,102,103,104,105,106} and communication guidelines^{1,2,107,108,109} is to help health professionals provide information in a way that it will be understood and recalled by their patients. Good communication is vital to facilitate patients' understanding of information because there is evidence that they often misunderstand terms used in consultations,^{110,111} and may find it difficult to process large amounts of information.¹¹² Checking patients' understanding of the information provided during consultations is considered to be an important communication skill as it allows doctors the opportunity to correct misunderstandings.^{107,109,113} Asking patients *if* they understand is not sufficient as patients often overestimate their comprehension.¹¹⁰ Thus, misunderstanding may be minimised if

patients' comprehension is verified by asking them *what* they have understood, rather than *if* they understand.¹¹⁰ In addition, actively encouraging patients' questions is recommended in communication guidelines as patients may not have the confidence to ask their doctor questions about the information provided during consultations.^{1,2,114} Furthermore, patients may need help to conceptualise or articulate their questions,^{115,116} and to clarify their need for information.¹¹⁷ Other communication behaviours that promote patients' understanding and recall of information include using in-consultation diagrams and illustrations,^{46,118,119} providing the most important information at the beginning of the consultation,¹²⁰ and summarising and repeating information.^{104,107,121}

Another important objective of many communication skills training modules and communication guidelines is to help health professionals elicit and respond empathically to patients' emotion. Doctors can allow and encourage patients to express their concerns and feelings by asking open questions, listening carefully, acknowledging concerns and feelings, and clarifying concerns and feelings.^{98,122} They can respond empathetically to patients' emotion by acknowledging, normalising and validating patients' concerns and feelings.^{98,122,123} In addition, doctors can respond to patients' verbal 'cues' for emotional support, (for example, *'I get so upset sometimes that I can't stop crying'*), patients' non-verbal cues (for example, facial expression and posture) and paraverbal cues (for example, auditory pitch and tone) indicating the need for emotional support.^{124,125} There is also a need for doctors to recognise the signs of anxiety and depression, particularly common in cancer patients, and to refer patients to psycho-social health professionals (counsellor, psychologist or psychiatrist) if appropriate.^{98,122,123}

The 'art of reassurance' is also perceived to be a central communication skill, regardless of the prognosis.^{104,126,127} Patients want doctors to convey information honestly while maintaining 'hope and optimism'.^{127,128}

1.2.2 Patient information needs

Cancer patients have high information needs, with the majority of patients wanting to be well informed about their diagnosis, including the specific medical name of the illness; their prognosis including their chances of cure and the extent of the disease spread; and their treatment options including potential side effects.^{129,130,131,132,133,134,135,136,137,138,139,}

^{140,141} The most common and preferred form of information for women with breast cancer is through doctor consultations.^{132,135,142} However, doctors may underestimate the amount of information that patients require.^{143,144} Many cancer patients also desire written information¹⁴⁵ and written information has been shown to be the second most preferred form of information after doctor consultations for women with breast cancer.¹⁴²

Meeting patients' information needs is important for enabling patient autonomy and informed consent and has been shown to assist in the development of a trusting doctor-patient relationship,¹⁴⁶ increase patients' understanding,¹¹³ and improve patients' psychological adjustment and perceived quality of life.^{130,147,148} Adequate information is also needed to ensure participation in treatment decision-making.^{138,149,150,151} However, most patients want to be fully informed regardless of whether they want to be involved in treatment decision-making.^{138,146,152} Patients who are satisfied with the information provided are also more likely to comply with medical recommendations and treatments.¹⁵³

The type and amount of information patients desire varies between individuals and may be affected by such factors as coping style,¹¹⁴ age,^{134,137} gender,^{133,154} ethnicity,¹⁵⁵ religious views,¹⁵⁴ and socio-economic status.¹³⁷ Information needs have also been shown to change over time for an individual patient.^{129,132,154} Responding to patients' verbal 'cues' for information, (for example '*I really don't know much about the different treatments*'), and patients' non-verbal cues and paraverbal cues indicating the need for information can help doctors meet patients' information needs.^{124,125} Furthermore, the type and amount of information provided can be tailored to the individual characteristics of each patient.^{156,157,158} Information can be tailored to individual characteristics such as demographic and disease characteristics including an individual's risk factors; behavioural characteristics

such as attitudes and intentions; individual processing of information such as coping style and locus of control beliefs; cultural characteristics; and theoretical concepts.¹⁵⁸

1.2.3 *Shared decision-making*

Shared decision-making refers to collaboration between patient and physician during the decision-making process.¹¹² One of the most cited goals of shared decision-making is to support medical decisions that are informed and coherent with patients' values.⁶ Shared decision-making is viewed as the preferred model for treatment decision-making.¹⁵⁹ Patient participation in decision-making is strongly advocated because it is consistent with the principles of patient autonomy and informed consent and has been shown to improve patients' quality of life,^{160,161} increase patients' motivation and compliance with treatment regimes,¹⁶² increase patients' satisfaction with care,¹⁶³ and enhance patients' control over their health care with more effective and patient-orientated decisions.⁵² Shared decision-making underlies many communication skills training modules.¹⁰⁴

However, not all patients may want or benefit from active involvement in treatment decision-making.^{131,138,150} Patient preferences for involvement in decision-making have been shown to be influenced by such factors as age, ethnicity, and education.^{134,155,164} and may change over time for an individual patient.^{129,154} There is some debate about what patients actually mean when they declare that they do or do not want to participate in decision-making.⁴⁷ Measures such as the Control Preference Scale that assess treatment decision-making preferences may be too simplistic to capture the complexity involved in treatment decision-making.^{129,146} Qualitative studies that explore treatment decision-making preferences^{146,165,166} and treatment decision-making experiences within the medical consultation and over time¹⁵¹ may better illuminate this complex area. For example, a qualitative study found that women strongly valued the sense of being involved in treatment decision-making but did not actually want to make the final decision about their care.¹⁴⁶ This finding was consistent with a longitudinal study that found that it was not having real treatment options that promoted psychological well-being, but rather having a doctor who fostered choice and involved the patient in determining the treatment plan.^{147,167}

Doctors need to ensure that they understand what patients actually mean when discussing their preferences for involvement in treatment decision-making.^{47,146,169}

A systematic review of shared decision-making summarised the essential elements of shared decision-making in one integrative model in medical encounters.⁶⁸ The essential elements include: a) defining/explaining the healthcare problem; b) presenting options; c) discussing pros/cons (benefits/risks/costs); d) clarifying patient values/preferences; e) discussing patient ability/self-efficacy; f) presenting what is known and make recommendations; g) checking/clarifying the patient's understanding; h) making or explicitly deferring a decision; and i) arranging follow up. Coding systems such as the OPTION, DSAT, and DAS-O systems have been developed which assess shared decision-making in oncology consultations.^{168,169}

Part 2 First stage of development of recommendations

2.1 Process of developing the Key Communication Elements (DCIS)

This thesis describes the first stage of development of recommendations for clinicians about communicating with women diagnosed with DCIS. It was beyond the scope of this thesis to conduct further stages required to develop rigorous evidence-based clinical practice guidelines such as establishing a multidisciplinary group of women with DCIS, clinicians, and researchers to oversee the development of the recommendations and review the evidence supporting the recommendations; and to conduct an extensive public consultation process involving members of the relevant professions and women with DCIS.¹⁷⁰

In this thesis, the first stage of development of recommendations for clinicians about communicating with women diagnosed with DCIS involved the following steps:

Step 1 *Systematic review of the experiences of women diagnosed with DCIS (see Chapter 1)*

Step 2 *Establishing the need for recommendations and the target audience for the recommendations*

Chapter 1 and *Chapter 2* demonstrated that there is a lack of understanding about DCIS and a desire for more information among women. These chapters highlighted the need to develop recommendations to assist doctors to effectively communicate about DCIS and improve women's understanding about their diagnosis. The target audience for the recommendations are clinicians involved in the care of women with DCIS.

Step 3 *Developing a comprehensive list of communication elements from the best available evidence including:*

1. the systematic review of the experiences of women diagnosed with DCIS described in *Chapter 1*
2. the cross-sectional study of Australian women with DCIS described in *Chapter 2*
3. the literature related to doctor-patient communication described in *Part 1* of this chapter

Key papers concerning the diagnosis and management of DCIS and invasive breast cancer were also used to ensure that the content of the communication elements was current and accurate.

Step 4 *Developing recommendations (see Table 3.1, Page 223) from the list of communication elements and structuring the recommendations into six communication components thought to be most relevant to clinicians:*

- A) Effectively communicating a diagnosis of DCIS
- B) Effectively communicating about DCIS prognosis
- C) Effectively communicating about treatment for DCIS
- D) Effectively providing information to women with DCIS
- E) Effectively providing support for women with DCIS
- F) Effectively providing information and support for women with DCIS from culturally and linguistically diverse (CALD) backgrounds

Step 5 *Providing examples of communication for clinicians to support each recommendation*

Step 6 *Conducting an initial pilot test of the perceptions of a convenience sample (n=7) of clinicians and senior health researchers about the Key Communication Elements (DCIS) (see Part 3, Page 220)*

2.2 Type of evidence used to inform recommendations

The Australian National Health and Medical Research Council (NHMRC) suggests that ideally recommendations should be based on systematic reviews of randomised controlled clinical trials.¹⁷⁰ However, it is recognised that non-randomised clinical trials and well-conducted observational studies (including longitudinal cohort studies and cross-sectional studies) and qualitative studies can offer valuable insight and are also important in developing recommendations.

As discussed above, the *Key Communication Elements (DCIS)* are based on the systematic review of the experiences of women diagnosed with DCIS described in *Chapter 1*, the cross-sectional study of Australian women with DCIS described in *Chapter 2*, and the literature related to doctor-patient communication described in *Part 1* of this chapter. It is acknowledged that the evidence concerning the experiences of women with DCIS is limited to descriptive studies (including observational studies and qualitative studies). There are

currently no randomised controlled clinical trials of communication interventions with women with DCIS. The literature relating to doctor-patient communication includes randomised controlled clinical trials of communication interventions with cancer patients (particularly in relation to information provision, psychological interventions, and emotional and social support) and descriptive studies (including observational studies and qualitative studies) mainly with cancer patients.

2.3 **Categorising the evidence**

There are many systems for grading evidence associated with recommendations about clinical practice. For example, the Australian National Health and Medical Research Council (NHMRC) developed levels of evidence, adapted from the US Preventative Services Task Force rating system.¹⁷⁰ The ‘level’ of evidence refers to the study design used to minimise bias: the highest level involves a systematic review of randomised controlled clinical trials.

Given that the evidence concerning the experiences of women diagnosed with DCIS is from descriptive studies, the NHMRC grading system was not considered to be the most appropriate method to categorise the evidence. The evidence used to develop the recommendations in the *Key Communication Elements (DCIS)* was categorised as follows (see Table 3.1, Page 223):

- (I) Intervention study (randomised controlled clinical trials and non-randomised clinical trials)
- (DS) Quantitative descriptive study
- (QS) Qualitative study
- (LR/G/T) Literature review of descriptive quantitative and/or qualitative studies; Guidelines; or Theory

2.4 Development of each recommendation from the evidence

Table 3.1 (see Page 219) presents the *Key communication elements for effectively communicating with women diagnosed with ductal carcinoma in situ (DCIS)*. How each recommendation was developed from the best available evidence is discussed below.

A. *Effectively communicating a diagnosis of ductal carcinoma in situ (DCIS)*

1. *Reassure the woman that she does not have breast cancer as we commonly understand it, that is, invasive breast cancer*

As demonstrated in the review in *Chapter 1* and the cross-sectional study in *Chapter 2*, the central concern and area of confusion for women with DCIS is whether they have ‘cancer’ or not.^{171,172,173} Women with DCIS have also been shown to experience unnecessary distress due to their lack of understanding about DCIS.^{173,174,175,176} Explaining to women with DCIS at the beginning of the consultation that they do not have ‘breast cancer as we commonly understand it’ aims to address their central concern, provide hope and reassurance to women,^{96,128} and optimise women’s understanding and recall of the information.^{113,120} Reassurance should be succeeded by information about *how* DCIS differs from invasive breast cancer as outlined in *Key Communication Element (DCIS) A3*.

2. *Tell the woman she has ductal carcinoma in situ (DCIS)*

Patients are considered to have a legal and moral right to accurate information about their diagnosis and the doctor has a duty to disclose information to the patient.¹⁰⁸ Furthermore, cancer patients have been shown to have high information needs with the majority of patients wanting to be well informed about their diagnosis, including the specific medical name of their illness.^{130,136,137} As demonstrated in the review in *Chapter 1*, few studies have assessed the information needs specifically of women diagnosed with DCIS. A cross-sectional study of women diagnosed with DCIS found that one third of women would have liked more information about their type of breast disease (see *Chapter 2*). Inadequate

information about the specific medical name of women's breast disease is likely to contribute to greater confusion among women with DCIS and to undermine a trusting doctor-patient relationship.¹⁴⁶

3. *Explain how DCIS differs from invasive breast cancer*

As demonstrated in the review in *Chapter 1* and the cross-sectional study in *Chapter 2*, there is confusion and misunderstanding among women diagnosed with DCIS about *how* DCIS differs from invasive breast cancer.¹⁷¹⁻¹⁷⁶ Unlike invasive breast cancer, DCIS cannot metastasize and a woman cannot die from DCIS unless it develops into invasive breast cancer.^{177,178,179} However, women with DCIS overestimate their risk of recurrence, metastases and dying from their disease.¹⁷³⁻¹⁷⁶ Inaccurate risk perceptions among women with DCIS have been shown to be associated with higher levels of distress.^{173,176} A cross-sectional study of women diagnosed with DCIS found that approximately half of women worried about their breast disease metastasizing, and that women who did not know that DCIS could not metastasize were more likely to worry about dying from DCIS (*see Chapter 2*).

Adequate information has been shown to increase patients' understanding,¹¹³ and improve psychological adjustment and perceived quality of life.^{130,147,148} A cross-sectional study of women diagnosed with DCIS found that approximately half of women would have like more information about whether their breast disease could metastasize, and that confusion about whether DCIS could metastasize was significantly associated with dissatisfaction with information (*see Chapter 2*). Explaining to women with DCIS *how* DCIS differs from invasive breast cancer is likely to increase women's understanding about DCIS and improve their psychological well-being.

4. *Use diagrams of DCIS and invasive breast cancer in the breast*

The National Breast and Ovarian Cancer Centre *Psychosocial Clinical Practice Guidelines: Information, Support and Counselling for Women with Breast Cancer*¹ recommend that

doctors use simple diagrams and illustrations where appropriate during consultations. In-consultation diagrams and illustrations have been shown to enhance patients' understanding and recall of information,^{46,118,119} and may assist women diagnosed with DCIS to understand how DCIS differs from invasive breast cancer.

5. *Check the woman's understanding about how DCIS differs from invasive breast cancer and clarify any misunderstanding*

Checking patients' understanding about their diagnosis is considered to be an important communication skill as it allows doctors the opportunity to correct misunderstandings.^{107,109} However, asking patients *if* they understand is not enough as patients often overestimate their comprehension.¹¹⁰ Given that women may experience difficulty in understanding how DCIS differs from invasive breast cancer, misunderstanding may be minimised if women's comprehension is verified by asking them *what* they have understood about the diagnosis rather than *if* they understand.

6. *Invite questions specifically about the diagnosis*

Actively encouraging patients' questions about the information provided during consultations is recommended because patients may not have the confidence to ask their doctor questions.^{1,2,114} Furthermore, patients may need help to conceptualise or articulate their questions.¹¹⁵ Inviting women with DCIS to ask questions specifically about the diagnosis and helping women to conceptualise or articulate their questions is likely to improve women's understanding about DCIS.

B. *Effectively communicating about DCIS prognosis*

1. & 2. Explain the natural history of DCIS and the uncertainties relating to the natural history of DCIS

There is general consensus that DCIS is a direct precursor to invasive breast cancer from the available laboratory and clinical data.^{177,179,180,181} However, not all DCIS will develop into invasive breast cancer.¹⁷⁷⁻¹⁸⁰ The best estimates are that 14%-53% of untreated DCIS may progress to invasive breast cancer over a period of ten years or more.¹⁷⁸ However, the estimates are derived from studies of cases of DCIS that were initially misdiagnosed as benign lesions and were treated with biopsy alone.¹⁷⁸ No direct observations of the natural history of DCIS are possible due to the current standard of surgical removal of the DCIS.¹⁸² Why and how often DCIS progresses to invasive breast cancer, the precise biologic pathway(s) between DCIS and invasive breast cancer, whether any subtypes of DCIS are more likely to progress than others, and how long after the DCIS diagnosis invasive breast cancer would develop is not well understood.^{180,183} These uncertainties complicate treatment decision-making for doctors and women with DCIS.

Although there is little empirical evidence about the impact on patients of communicating the uncertainties related to the medical evidence nor the optimal opportunities for communicating these uncertainties to patients, many ethicists and researchers urge doctors to express uncertainty to patients to promote realistic patient expectations, enable informed consent, and ensure a greater level of shared decision-making.^{7,20,27,67-69} Furthermore, Epstein and Street have recently proposed a framework of the goals of medical communication and distinguished ‘managing uncertainty’ as one of the functions of doctor-patient communication.^{4,5}

As demonstrated in the review in *Chapter 1*, few studies have assessed women’s knowledge of the uncertainties relating to the natural history of DCIS or women’s perceptions of whether doctors should communicate these uncertainties to them. A cross-sectional study of women diagnosed with DCIS found that only 19% of women were aware

that not *all* women with DCIS would develop invasive breast cancer if the DCIS was left untreated (*see Chapter 2*). Similarly, three qualitative studies found that only some women with DCIS were aware of some of the uncertainties surrounding the natural history of DCIS.^{172,173,184} Only one study discussed women's perceptions of whether doctors should communicate the uncertainties to them.¹⁷² The study found that women wanted more information about the uncertainties relating to DCIS.¹⁷²

3. *Explain the provisional nature of prognostic information*

Women with DCIS are usually diagnosed after a stereotactic core biopsy of the breast tissue under local anaesthesia.¹⁸² The pathology report following a biopsy includes information about prognostic factors such as the size of the DCIS, nuclear grade, necrosis, biopsy margins, micro-invasion (if found), and invasive breast cancer (if found). However, stereotactic core biopsy may miss invasive breast cancer in about 15% of women initially diagnosed with DCIS.^{181,185} The pathology report after women with DCIS undergo breast surgery is needed to confirm the absence of invasive breast cancer. It will also confirm prognostic factors such as nuclear grade, necrosis, and microinvasion and provide further information about the size of the DCIS and surgical margins.

Making provisional diagnoses and decisions with patients allows for changing priorities and circumstances over time and has been suggested as a strategy for doctors to help them manage one area of uncertainty with patients.^{49,60,70} Therefore, women with DCIS would be likely to benefit from being informed in the initial diagnostic consultation that more information will be obtained when the pathologist examines the breast tissue after surgery and that this information will affect decisions about treatment.

Furthermore, recommendations for 'breaking bad news' include preparing the patient for the possibility of cancer as early as possible in the diagnostic process, such as when the patient requires further tests.¹⁰⁹ Patients have also been found to experience lower anxiety about a cancer diagnosis if the doctor prepared the patient for this possibility.¹²¹ Therefore, women with DCIS would be likely to benefit from being informed should be informed that

invasive breast cancer may be detected during surgery. However, honesty needs to be balanced against maintaining hope and providing reassurance to patients.^{96,126-128} Women with DCIS need to be reassured that they do not, at this stage, have invasive breast cancer and that the likelihood that invasive breast cancer will be detected during surgery is small.

4. Explain the currently known DCIS prognostic factors

Not all DCIS will progress to invasive breast cancer.¹⁷⁷⁻¹⁸¹ Identifying subtypes of DCIS that are more likely to progress than others is a high priority. Prognostic factors such as nuclear grade, tumour size, margin status, and age have been identified as important predictors of local invasive and DCIS recurrence.^{179,181,186, 187,188} Molecular and genetic studies are currently trying to identify more precise prognostic markers.^{177,179} Identifying better prognostic markers will lead to optimal individualised therapy with minimal overtreatment.^{177,179-181} Explaining the prognostic factors to women with DCIS may allow women to better understand their prognosis (in terms of their likelihood of DCIS recurring or of developing invasive breast cancer in the breast) and assist women in treatment decision-making.

C. Effectively communicating about treatment for DCIS

1. Explain the aim and importance of treatment

The aim of treatment for DCIS is to prevent invasive breast cancer from developing in the breast.^{177,179,180,183} It is important that invasive breast cancer is prevented because invasive breast cancer can spread outside the breast and cause death. However, the critical difference between the prevention goal of DCIS treatment and the therapeutic goal of invasive breast cancer may not be well appreciated by women with DCIS,¹⁸⁹ as suggested by women's overestimated risk perceptions of recurrence, metastases and dying from their disease.¹⁷³⁻¹⁷⁶ Explaining the aim and importance of treatment to women with DCIS should assist women to make better informed decisions about treatment.

2. *Reassure the woman of an excellent prognosis after treatment*

Survival rates following treatment for DCIS are high, with the overall ten-year mortality rate after treatment for DCIS being less than 2%.¹⁹⁰ Most women diagnosed and treated for DCIS will not develop invasive breast cancer.^{187,191} The risk of developing invasive breast cancer after treatment for DCIS will depend on the woman's prognostic factors and the type of treatment.^{186,187} A randomised control trial found that the *overall* ten year local invasive recurrence free rate was 92% in women treated by breast conserving surgery and radiotherapy and 87% in women treated by breast conserving surgery alone.¹⁹¹ The risk of developing invasive breast cancer after a mastectomy is less than 1%.¹⁸⁷ Women with DCIS have been shown to overestimate their risk of developing invasive breast cancer recurrence.¹⁷⁴⁻¹⁷⁶ Reassuring women with DCIS of an excellent prognosis after treatment provides women with honest information about their prognosis and may help women maintain hope and manage uncertainty by enabling 'positive reappraisal' of the meaning of the diagnosis, for example, "this diagnosis does not signal death".^{78,80,126-128}

3.-7. *Treatment decision-making*

As demonstrated in the review in *Chapter 1*, few studies have assessed the experience of treatment decision-making in women with DCIS. A cross-sectional study of women diagnosed with DCIS found that approximately half of women with DCIS experienced high decisional conflict in treatment decision-making (*see Chapter 2*). Qualitative studies have found that women with DCIS experience difficulties in treatment decision-making such as understanding why they are recommended treatments also used to treat invasive breast cancer, especially a mastectomy, when they do not have 'real' breast cancer;^{171,172,184} understanding whether treatment is really necessary given the uncertainty about whether their DCIS would develop into invasive breast cancer;^{172,184} and understanding why certain treatment options are not recommended to individual women.¹⁹²

Adequate information is needed to ensure participation in treatment decision-making^{149,150} and to help patients reduce the uncertainty associated with illness and treatment.^{78,80,86}

Furthermore, the majority of patients want to be well informed about their treatment and prognosis after treatment.^{129,133,137,141} However, little is known about the satisfaction of women with DCIS with the information provided about their treatment including treatment options and treatment effectiveness (*see Chapter 1*). A cross-sectional study of women diagnosed with DCIS found that most women were satisfied with the information about treatment options (*see Chapter 2*). However, 44% of women would have liked more information about the chances of developing breast cancer after treatment.

The perceived level and satisfaction with women's involvement in treatment decision-making have been assessed in only a few studies with women diagnosed with DCIS. A cross-sectional study of women diagnosed with DCIS (*see Chapter 2*) and a qualitative study¹⁹² found that most women with DCIS made treatment decisions with their doctors. One study reported that most women with DCIS were satisfied with their 'ability to make treatment decisions'.¹⁹³

Shared decision-making is viewed as the preferred model for treatment decision-making.¹⁵⁹ Shared decision-making involves collaboration between patient and physician during the decision-making process.¹¹² One of the most cited goals of shared decision-making is to support medical decisions that are informed and coherent with patients' values.⁶ The *Key Communication Elements (DCIS)* are based on the premise that adequate access to information is essential and that shared decision-making should be encouraged and offered to women with DCIS. The *Key Communication Elements (DCIS)* related to treatment decision-making have been developed from the essential elements of shared decision-making outlined in the Makoul *et al* model⁶⁸ and the items in coding systems such as the OPTION, DSAT, and DAS-O systems which assess shared decision-making in oncology consultations.^{168,169}

9. *Discuss any physical symptoms with the woman related to her treatment and how to manage them*

Treatment options for women with DCIS include breast surgery (breast conserving surgery or mastectomy), radiotherapy (after breast conserving surgery), and hormonal treatments.^{181,182,194} Women with DCIS are not treated with chemotherapy, and sentinel node biopsy or axillary lymph node dissection is not routinely performed during breast surgery.^{177,182,194} There is also some debate about the use of hormonal treatments in women with DCIS and the use of radiotherapy in all subtypes of DCIS.^{177,179,181,191} Therefore, women diagnosed and treated for DCIS might be expected to experience similar treatment-related physical symptoms to women with invasive breast cancer associated with breast surgery, and in some women, radiotherapy and hormonal treatments. However, women with DCIS would be expected to less commonly experience lymphedema and would not be expected to experience chemotherapy-induced symptoms such as nausea, vomiting, and chemotherapy-related fatigue.

Women with invasive breast cancer have been shown to experience a number of treatment-related physical symptoms that affect their quality of life.¹ However, as demonstrated in the review in *Chapter 1*, few studies have assessed treatment-related physical symptoms in women with DCIS. A large longitudinal cohort study found that women with DCIS have good long term physical health and functioning but may experience some short term effects (within six months of the diagnosis) of treatment such as limitations in role functioning due to physical problems.¹⁹⁵ A qualitative study found that some women with DCIS experienced pain and discomfort after surgery particularly after a mastectomy.¹⁷² Furthermore, women with DCIS may experience less negative effects of treatment than women with invasive breast cancer due to differences in treatment. A cross-sectional study surveyed women 2-3 years after treatment and found that women with DCIS perceived that the disease and treatment had a *positive* impact on their physical health compared to women with invasive breast cancer who perceived that the disease and treatment had a negative impact on their physical health. Women with DCIS in the study were significantly less likely to have radiotherapy, sentinel node biopsy or hormonal therapy than women with

invasive breast cancer. The results are also most likely an example of ‘posttraumatic growth’ or ‘benefit finding’.¹⁹⁶

Discussing the physical symptoms with women diagnosed with DCIS related to treatment and how to manage them is likely to improve the quality of life in women with DCIS and help women manage one source of uncertainty related to their illness and treatment.^{78,80}

10. *Sensitively discuss sexual and body image issues during treatment decision-making and after treatment*

Women diagnosed with invasive breast cancer have been shown to experience sexual and body image problems as a result of their diagnosis and treatment.^{197,198} Women diagnosed and treated for DCIS might be expected to experience similar sexual and body image problems to women with invasive breast cancer associated with breast surgery, and in some women, hormonal treatments. As demonstrated in the review in *Chapter 1*, there are no data available about women’s perceptions of the impact of the diagnosis and treatment of DCIS on their sexuality and body image in the short term (within six months of the diagnosis). Women diagnosed with invasive breast cancer experience sexual and body image problems as a result of their diagnosis and treatment.^{197,198} Women diagnosed and treated for DCIS might be expected to experience similar sexual and body image problems to women with invasive breast cancer associated with breast surgery, and in some women, hormonal treatments. None of the studies assessed women’s perceptions of the impact of the diagnosis and treatment of DCIS on their sexuality and body image in the first year after diagnosis. Two quantitative studies^{193,199} and one qualitative study¹⁷² examined women’s perceptions in the long term and found that women with DCIS perceived that the disease and treatment had a negative impact on their sexuality. However, women with DCIS may experience less negative effects of treatment on their sexuality than women with invasive breast cancer due to differences in treatment. A cross-sectional study surveyed women at 2-3 years after treatment and found that women with DCIS perceived that the disease and treatment had a *positive* impact on their sex life compared to women with invasive breast cancer who perceived that the disease and treatment had a negative impact on their sex

life.¹⁷⁵ Women with DCIS in the study were significantly less likely to have hormonal therapy than women with invasive breast cancer. The results are also most likely an example of ‘posttraumatic growth’ or ‘benefit finding’.¹⁹⁶

The National Breast and Ovarian Cancer Centre *Psychosocial Clinical Practice Guidelines: Information, Support and Counselling for Women with Breast Cancer*¹ recommend that doctors should routinely discuss the impact of treatment on women’s sexuality and body image to assist in treatment decision-making, detect and manage any sexual problems, and refer women to psycho-social health professionals (counsellors, psychologists or psychiatrists) if appropriate. The guidelines acknowledge that there is a need to discuss sexual and body image issues sensitively with women and to follow women’s cues for privacy or disclosure.

11. *Discuss physical activity after treatment*

Reduced physical activity and weight gain have been shown to be common among women following the diagnosis and treatment of invasive breast cancer.^{200,201,202} Weight gain is associated with increased risk of developing diabetes and cardiovascular disease.²⁰³ Women who are physically active after a diagnosis of invasive breast cancer have also been shown to have a lower risk of cancer recurrence and cancer related death compared with inactive women.^{204,205,206}

Two longitudinal cohort studies found that women with DCIS decreased their physical activity and increased their weight and body fat following the diagnosis.^{202,207} However, greater weight and body fat gains were found in women with invasive breast cancer compared to women with DCIS.²⁰² Among women with DCIS and invasive breast cancer, greater increases in weight were found in women who were younger age, postmenopausal, and who decreased their physical activity.²⁰² Women were more likely to decrease their physical activity if they had a mastectomy or were more anxious.²⁰⁸ Discussing the benefits of physical activity with women diagnosed and treated for DCIS and the reasons for any

physical inactivity is likely to improve the level of physical activity in women with DCIS and improve women's physical and psychological well-being.

D. Effectively providing information to women with DCIS

Communication behaviours that promote patients' understanding and recall of information provided during consultations include telling the patient the most important information at the beginning of the consultation;^{113,120} using diagrams;^{46,118,119} checking the patient's understanding of the information provided and clarifying any misunderstanding;^{107,109,110} inviting questions;^{1,2,114} responding to the patient's cues (indirect statements) for information;^{124,125} summarising and repeating information;^{104,107,121} tailoring information to the patient's needs and characteristics where possible;^{156,158} and providing patients with written information.^{142,145}

Women diagnosed with DCIS have reported that they wanted more written information about DCIS (*see Chapter 2*), information about DCIS to be repeated in follow-up consultations (*see Chapter 2*), and advice about appropriate websites, books or articles for further information about DCIS.¹⁷²

E. Effectively providing support for women with DCIS

1. Respond to emotion

As demonstrated in the review in *Chapter 1* and the cross-sectional study in *Chapter 2*, many women with DCIS describe the experience of being diagnosed and treated for DCIS as a stressful and difficult time.^{171-173,184} Women with DCIS have also been shown to experience a high level of 'cancer-specific worry'^{173,193} or 'intrusive or avoidant thoughts' in response to their diagnosis.¹⁷⁶ A large longitudinal cohort study found that women with DCIS experience short term (within six months of the diagnosis) decline in their general mental health.¹⁹⁵ The study found that women with DCIS had good general mental health in the long term.¹⁹⁵

Clinicians are responsible for the psychosocial care of their patients as well as their surgical and medical care.² Women with invasive breast cancer perceive clinicians as a considerable source of emotional support for themselves and their families, looking particularly to the surgeon, the oncologist and their general practitioner.²⁰⁹ Women diagnosed with DCIS have also been shown to value the emotional support from clinicians, and most women with DCIS have been found to be very satisfied with the level of emotional support they received from their primary clinician.^{171,176,192,193}

Providing patients with the opportunity to discuss their feelings has been shown to decrease their psychological distress.^{210,211} Doctors can provide emotional support to patients by allowing and encouraging patients to express their concerns and feelings (by asking open questions, listening carefully, acknowledging concerns and feelings, clarifying concerns and feelings) and by responding with empathy (by acknowledging, normalising and validating patients' concerns and feelings).^{98,122,123} In addition, doctors need to respond to patients' verbal and nonverbal 'cues' for emotional support.^{124,125} Doctors should also be aware of the signs of anxiety and depression, particular common among cancer patients, and to refer patients to psycho-social health professionals (counsellors, psychologists or psychiatrists) if appropriate.^{98,122,123}

2. *Avoid minimising the impact of the diagnosis and treatment of DCIS*

A qualitative study found that some women with DCIS perceived that their health professionals minimised the emotional impact of the diagnosis of DCIS.¹⁷² Although women were partly reassured by a better prognosis, women felt they had to cope with the uncertainties involved in their diagnosis and had to undergo treatments similar to women with invasive breast cancer and therefore needed the same level of emotional support that health professionals provided to women with invasive breast cancer.

3. *Acknowledge and help manage uncertainty*

Women diagnosed with DCIS must cope with various diagnostic, prognostic and treatment uncertainties in addition to the uncertainties inherent in the experience of illness. It is beyond the scope of the aims of the *Key Communication Elements (DCIS)* to develop a detailed uncertainty management plan for doctors to help women with DCIS manage uncertainty. Although it is clear that patients need information to help manage uncertainty,^{79,80} it is not clear whether cognitive-behavioural strategies and extensive psychosocial support for uncertainty should be provided during routine clinical care or if specialised psychological interventions are necessary.⁴

The following basic strategies for acknowledging and helping patients manage uncertainty may be of some benefit to women with DCIS: providing verbal and written information about what is currently known about the diagnosis, prognosis, and treatment of DCIS including treatment side effects and how to manage them;^{72,78-80} explaining to women what is currently *not* known about the diagnosis, prognosis, and treatment of DCIS;^{4,7,27,65,67} identifying any areas of concern for the individual woman, assisting with problem-solving and providing information where available;^{72,82} enabling the woman's 'positive reappraisal' of the meaning of the diagnosis, for example, "*this diagnosis does not signal death*";^{78,80} allowing and encouraging the woman to express her concerns and feelings about any areas of uncertainty and responding with empathy;^{98,122,123} and encouraging the woman to utilise her social support system.^{72,86}

4. *Assess the woman's level of support from a partner, family, friends and social support networks.*

Invasive breast cancer and its treatment can place considerable strain on relationships, particularly in situations where difficulties existed before the diagnosis.¹ As demonstrated in the review in *Chapter 1*, only one study assessed the impact of the diagnosis and treatment of DCIS on women's relationships during the first year after diagnosis.¹⁷⁴ The cross-sectional study surveyed women shortly after surgery and found that only a small

percentage of women with DCIS, and women with invasive breast cancer, experienced a negative impact of the diagnosis and treatment on their relationships.¹⁷⁴ In the long term, women with DCIS and women with invasive breast cancer were found to perceive a similar *positive* impact of the diagnosis and treatment on their family relations, relatives, spouse, friends and acquaintances,¹⁷⁵ another example of ‘posttraumatic growth’ or ‘benefit finding’.¹⁹⁶

Social support from a partner, family, friends and support networks has been identified as an important factor in women’s adjustment to invasive breast cancer.^{212,213,214} A qualitative study with women diagnosed with DCIS found that women felt that support from their family helped women most to cope with their diagnosis and treatment.¹⁷² Patients’ emotional or physical problems may disrupt their normal social activities and prevent them from getting the support that would assist their adjustment to the illness. A large longitudinal cohort study found that women with DCIS experience short term (within six months of the diagnosis) decline in their ‘social functioning’.¹⁹⁵ The study found that women with DCIS had good ‘social functioning’ in the long term.¹⁹⁵

The National Breast and Ovarian Cancer Centre *Psychosocial Clinical Practice Guidelines: Information, Support and Counselling for Women with Breast Cancer*¹ recommend that doctors should ask women about their key support people and define the level of involvement of these people, with particular attention given to women’s partners. The Guidelines also recommend that doctors should encourage and help women to use existing sources of positive social support and assist in finding support networks. Women’s social support systems can also help women to manage uncertainty by assisting women to acquire and interpret information, maintain a positive attitude, and by providing emotional support.^{72,86,95}

5. *Provide information about support groups and services*

Professionally-run support groups,²¹⁵ peer support groups,²¹⁶ telephone counselling,²¹⁷ and Internet support groups²¹⁸ have been shown to improve the emotional wellbeing of women

with invasive breast cancer. Qualitative studies with women diagnosed with DCIS found that some women benefited from support groups for women with invasive breast cancer.^{171,172} However, some women wanted support groups specifically for women with DCIS, including Internet support groups, to address their particular issues and concerns and ‘reduce the isolation of the diagnosis’.^{171,172}

F. Effectively providing information and support for women with DCIS from culturally and linguistically diverse (CALD) backgrounds

As demonstrated in the review in *Chapter 1*, a lack of understanding about DCIS may be even more pronounced in women from culturally and linguistically diverse (CALD) backgrounds.^{192,219} For example, Latina US women have been found to be more confused about whether they had ‘cancer’ or not, more likely to view their diagnosis as life-threatening, and reported more psychological distress than non-Latina white US women.¹⁹² Chinese Canadian women with DCIS have also been found to have poor knowledge about DCIS, with only a minority of women understanding that their type of ‘breast cancer’ was confined to the milk ducts in the breast.²¹⁹ The treatment decisions of Chinese Canadian women with DCIS also reflected a lack of understanding about DCIS with women preferring to be treated by a mastectomy even in situations when breast conserving surgery was the recommended option. Treatment decisions were found to be strongly influenced by the woman’s husband, other family members, Chinese-speaking family physicians and friends. Chinese Canadian women with DCIS sought additional information from the Chinese Cancer Hotline and reported that they needed more information support in Chinese languages (Cantonese and Mandarin).

Australia is one of the most culturally and linguistically diverse (CALD) countries in the world with hundreds of languages spoken, most of the world’s religions practiced and 23 per cent of Australians born overseas (Australia Bureau of Statistics 2001). People who live in Australia come from diverse social, political and economic backgrounds, and have a wide range of experiences, behaviours, and beliefs in relation to health and illness.^{1,97,220}

The National Breast and Ovarian Cancer Centre *Psychosocial Clinical Practice Guidelines*:

*Information, Support and Counselling for Women with Breast Cancer*¹ recommends that health professionals be aware and sensitive to cultural differences in women's values, interpretations and behaviour; involve family members of women from CALD backgrounds in treatment decision-making; use professional interpreters if a woman is not proficient in English, and provide written information in a woman's first language if available.

Part 3 Reviewers' feedback about the Key Communication Elements (DCIS)

An initial pilot test was conducted to test the face validity of the *Key Communication Elements (DCIS)* with a convenience sample (n=7) of clinicians and senior health researchers known to the National Breast and Ovarian Cancer Centre (NBOCC), Sydney, Australia, including oncologists (n=3), a pathologist who was employed as the clinical director of a BreastScreen service, and senior health researchers (n=3) specialising in cancer and doctor-patient communication.

The reviewers were asked to provide written feedback about the *Key Communication Elements (DCIS)* in terms of the following:

- the accuracy of the content
- the understandability of the recommendations
- the relevance of the recommendations for clinical practice
- the suitability of using the recommendations in communication skills training for clinicians working in oncology

Overall, the reviewers thought the *Key Communication Elements (DCIS)* were well presented, accurate, understandable, relevant to clinical practice, suitable for communication skills training, and highlighted the difficult aspects of communicating with women diagnosed with DCIS.

Subsequent to the reviewers' feedback, minor changes in content were made in the following 6 areas:

1) *Explaining the diagnosis using diagrams*

The *Key Communication Elements (DCIS)* were amended to include information about using a diagram of the breast to explain the difference between DCIS and invasive breast cancer.

2) *Explaining the natural history of DCIS*

The *Key Communication Elements (DCIS)* were amended to include that *some* women rather than *most* women with DCIS will never develop breast cancer if they are not treated, to reflect current understanding about the natural history of DCIS. The *Key Communication Elements (DCIS)* were also amended to include information that current research hopes to discover more precise prognostic factors.

3) *Making a provisional diagnosis*

The *Key Communication Elements (DCIS)* were amended to include that women with DCIS should be informed before they have surgery that the diagnosis of DCIS is a provisional diagnosis and that there is a possibility that invasive breast cancer will be detected during surgery. Women also need to be reassured that they, at the stage before surgery, do not have invasive breast cancer.

4) *Explaining treatment for DCIS*

The *Key Communication Elements (DCIS)* were amended to include information about the following: a) the importance of treatment; b) the benefit of radiotherapy for women with small, low grade DCIS is less than for women with larger, higher grade DCIS; c) the option of no treatment; d) situations in which one or more lymph nodes may need to be removed;

e) the effect of surgery on women's body image; and f) the risk of invasive breast cancer and DCIS recurrence after breast conserving surgery *with* and *without* radiotherapy.

5) *Offering the opportunity to delay treatment decisions*

The *Key Communication Elements (DCIS)* were amended to include that women should be offered the opportunity to delay treatment decisions.

6) *Reassuring women of excellent prognosis after treatment for DCIS*

The *Key Communication Elements (DCIS)* were amended to emphasise the important of reassuring women of the likelihood of cure after treatment for DCIS and to clarify the excellent prognosis in terms of the low rate of local recurrence.

Table 3.1 (see Page 223) presents the amended *Key communication elements for effectively communicating with women diagnosed with ductal carcinoma in situ (DCIS)* and includes a description of each recommendation, examples of communication for clinicians, and the sources of evidence (and methodology) used in the development of each recommendation.

Table 3.1: Key communication elements for effectively communicating with women diagnosed with ductal carcinoma in situ (DCIS)

*Key: I Intervention study DS Quantitative descriptive study QS Qualitative study LR/G/T Literature review of descriptive studies; Guidelines; or Theory

Key Communication Elements (DCIS)	Examples of communication	Evidence			
		Women's experiences of DCIS literature*	Communication literature*	DCIS diagnosis & management literature	Invasive breast cancer management literature
A. Effectively communicating a diagnosis of ductal carcinoma in situ (DCIS)					
1. Reassure the woman that she <u>does not</u> have breast cancer as we commonly understand it, that is, invasive breast cancer	<i>“The good news is you do not have breast cancer as we commonly understand it.”</i>	DS (173-176, 193) QS (171, 172, 184, 192)	DS (96, 110, 126) QS (127) LR/G/T (113, 120, 128)		
2. Tell the woman she has ductal carcinoma in situ or DCIS	<i>“What you have is called ductal carcinoma in situ or DCIS.”</i>	DS (173)	DS (130, 136, 137) LR/G/T (109)		
3. Explain how DCIS differs from invasive breast cancer:					
i. Explain that DCIS cannot spread and cause death unlike invasive breast cancer	<i>“Ductal carcinoma in situ or DCIS is <u>not</u> breast cancer as we commonly understand it because it <u>cannot</u> spread outside the milk ducts into other parts of the breast or to other parts of the body.”</i>	DS (173-176, 193) QS (171, 172, 184, 192)	I (147) DS (130, 148) LR/G/T (113)	177-183, 186-191	
ii. Explain the tissue pathology, that is, that the abnormal cells are contained in the milk ducts of the breast in DCIS unlike in invasive breast cancer in which they have spread outside the milk ducts	<i>“In DCIS the abnormal cells are contained in the milk ducts of the breast. ‘In situ’ means ‘in place’. DCIS cannot spread outside the milk ducts into other parts of the breast or to other parts of the body. You cannot die from DCIS unless it develops into ‘invasive’ breast cancer.”</i> <i>"Breast cancer as we commonly understand it is called “invasive” breast cancer. In “invasive”</i>				

Key Communication Elements (DCIS)	Examples of communication	Evidence			
		DCIS women's experiences literature*	Communication literature*	DCIS diagnosis & management literature	Invasive breast cancer management literature
	<i>breast cancer, the abnormal cells have spread out of the milk ducts into the surrounding breast tissue. 'Invasive' breast cancer unlike DCIS can then spread outside the breast to other parts of the body and can cause death."</i>				
4. Use diagrams of DCIS and invasive breast cancer in the breast			I (46, 119) LR/G/T (1, 118)		
5. Check the woman's understanding about how DCIS differs from invasive breast cancer and clarify any misunderstanding	<i>"I just want to make sure that I have communicated clearly the type of breast disease you have. How do you understand the difference between your breast disease and breast cancer as we commonly think of it?"</i> <i>"I just want to make sure that I have communicated clearly. Tell what you understand about your diagnosis from what I have said so far?"</i>		DS (110) LR/G/T (107, 109)		
6. Invite questions specifically about the diagnosis: the woman may also need help to conceptualise or articulate her questions	<i>"Are you unsure about anything I have said about your diagnosis?"</i> <i>"Do you want to ask me any questions about your diagnosis?"</i> <i>"Do you want me to go over what I have said about how DCIS differs from invasive breast</i>		DS (114, 115) LR/G/T (1, 2)		

Key Communication Elements (DCIS)	Examples of communication	Evidence			
		DCIS women's experiences literature*	Communication literature*	DCIS diagnosis & management literature	Invasive breast cancer management literature
	cancer?"				
B. Effectively communicating about DCIS prognosis					
1. Explain the natural history of DCIS: Explain DCIS as a <u>precursor</u> to invasive breast cancer	<i>"If the DCIS is not treated it may develop into invasive breast cancer which can spread outside the breast to other parts of the body."</i>			177-183, 186-191	
2. Explain the uncertainties relating to the natural history of DCIS:					
i. Explain that not all women with DCIS will develop invasive breast cancer if they are not treated, that is, some women with DCIS will never develop breast cancer if they are not treated	<i>"Some women with DCIS will develop invasive breast cancer if they are not treated for DCIS and some women will not have any problems. However, it is not possible to precisely predict which women with DCIS would develop invasive breast cancer if they were not treated as all women are recommended to have treatment. Nor do we reliably know how many with DCIS will develop invasive breast cancer if they were not treated. Nor how long after the diagnosis of DCIS an invasive breast cancer would develop."</i>	DS (173) QS (171, 172, 184)	LR/G/T (4-7)	177-183, 186-191	
ii. Explain the uncertainty about knowing which DCIS women would develop invasive breast cancer					
iii. Explain the uncertainty about the exact proportion of DCIS women who would develop invasive breast cancer	<i>"All women are recommended to have treatment for DCIS. Therefore, the exact proportion of women with DCIS who will later develop invasive breast cancer if they are not treated is not known. Studies have estimated</i>				
iv. Explain the uncertainty about knowing					

Key Communication Elements (DCIS)	Examples of communication	Evidence			
		DCIS women's experiences literature*	Communication literature*	DCIS diagnosis & management literature	Invasive breast cancer management literature
how long after the DCIS diagnosis invasive breast cancer would develop	<p><i>that overall 14-53% of DCIS women will develop invasive breast cancer over a period of ten years or more but these studies have poor reliability and group all sub types of DCIS together."</i></p> <p><i>"Because DCIS may develop into invasive breast cancer and invasive breast cancer can spread and cause death, all women with DCIS are recommended to have treatment."</i></p>				
3. Explain the provisional nature of prognostic information: <i>In the initial diagnostic consultation:</i> <ol style="list-style-type: none"> Explain that more information will be obtained when the pathologist examines the breast tissue removed during surgery Explain that the information in the pathology report will affect decisions about treatment Explain that invasive breast cancer may be found during surgery Reassure the woman that, at this stage, she does not have invasive breast cancer 	<p><i>"The pathologist will examine the breast tissue removed during surgery. The pathology results will usually be available a few days after surgery."</i></p> <p><i>"The pathology report has information that will affect your decisions about treatment."</i></p> <p><i>"Occasionally, during surgery an area of invasive breast cancer may be found. This will affect your decisions about treatment. However, at this stage, I can reassure you that you do not have invasive breast cancer."</i></p>		DS (53, 96, 126) QS (60, 127) LR/G/T (49, 70, 109, 128)	177-183, 186-191	

Key Communication Elements (DCIS)	Examples of communication	Evidence			
		DCIS women's experiences literature*	Communication literature*	DCIS diagnosis & management literature	Invasive breast cancer management literature
	and that the likelihood that invasive breast cancer will be detected during surgery is small				
4. Explain the currently known DCIS prognostic factors: <i>After surgery:</i> <ol style="list-style-type: none"> Explain that the pathology report reports on the features of the DCIS such as the size, nuclear grade, surgical margins and whether there are any areas of invasive breast cancer or microinvasion Explain the features of a woman's DCIS which make her more or less likely to develop invasive breast cancer eg high nuclear grade, larger size, positive surgical margins, and microinvasion increase the risk of developing invasive breast cancer and DCIS coming back in the breast Explain that current research hopes to discover more precise prognostic factors 	<p><i>"More information about the size and features of the DCIS will be found in the pathologist's report after surgery. The pathologist will look at the size of the abnormal area and whether there is a rim of healthy breast tissue around the abnormal area. This is called the surgical margin. The rim of healthy tissue around the abnormal cells is needed to make sure that all the abnormal area has been removed. The pathologist will also look at the grade of the abnormal cells. For example, high grade means that the cells look more abnormal and are more active or faster growing than low grade cells."</i></p> <p><i>"Your pathology report after a breast biopsy and after surgery will tell us the features of your DCIS. Some features of the DCIS make it more or less likely to develop into invasive breast cancer. For example, a larger area of DCIS, or DCIS that is in more than one part of the breast, is more likely to develop into invasive breast cancer than small DCIS, or DCIS in one part of the breast. Also, DCIS that is high grade may be</i></p>	DS (53) QS (60) LR/G/T (49, 70, 109)	177-183, 186-191		

Key Communication Elements (DCIS)	Examples of communication	Evidence			
		DCIS women's experiences literature*	Communication literature*	DCIS diagnosis & management literature	Invasive breast cancer management literature
	<p>more likely to develop into invasive breast cancer than low nuclear grade DCIS. High grade means that the DCIS cells look more abnormal and are more active or faster growing than low grade DCIS. <u>However</u>, even if you have one or more of these features you may never develop invasive breast cancer."</p> <p>"Current research aims to help doctors better predict which women with DCIS will develop invasive breast cancer."</p>				
<i>C. Effectively communicating about treatment for DCIS</i>					
1. Explain the aim and importance of treatment: <ul style="list-style-type: none"> i. Explain that treatment for DCIS aims to remove the DCIS to help prevent invasive breast cancer from developing in the breast OR that if the DCIS is not treated it can develop into invasive breast cancer ii. Explain that invasive breast cancer is a serious condition that can spread and cause death 	<p>"Treatment for DCIS aims to remove the DCIS to help prevent invasive breast cancer from developing in the breast.</p> <p>"In most women treatment for the DCIS results in complete cure. However, if the DCIS is not treated it can develop into invasive breast cancer which is a serious condition that can spread and cause death."</p>			177-183, 186-191	

Key Communication Elements (DCIS)	Examples of communication	Evidence			
		DCIS women's experiences literature*	Communication literature*	DCIS diagnosis & management literature	Invasive breast cancer management literature
2. Reassure the woman of an excellent prognosis after treatment: <ul style="list-style-type: none"> i. Explain that most women diagnosed and treated for DCIS will not develop invasive breast cancer or DCIS again in that breast OR that treatment for DCIS usually results in a low risk of developing invasive breast cancer or of the DCIS coming back ii. Explain that in most women treatment for the DCIS results in 'complete cure' 	<p><i>"The good news is that DCIS can be treated very successfully and most women diagnosed and treated for DCIS will not have any further problems."</i></p> <p><i>"In other words, after treatment for DCIS most women will not develop invasive breast cancer or DCIS again. Treatment for DCIS usually results in a low risk of developing invasive breast cancer or of the DCIS coming back."</i></p> <p><i>"In most cases, treatment for DCIS results in complete cure."</i></p>	<p>DS (174-176)</p>	<p>I (78, 80)</p> <p>DS (126)</p> <p>QS (127)</p> <p>LR/G/T (128)</p>	<p>177-183, 186-191</p>	
3. Involve the woman and her family in treatment decision-making: <ul style="list-style-type: none"> i. Acknowledge that there are treatment choices ii. Introduce shared decision-making and say why it is important iii. Make partnership statements iv. Discuss the woman's values, preferences and concerns about 	<p><i>"I'm going to tell you something about different treatments but I would like you to participate in the decision-making itself."</i></p> <p><i>"There are several options for treatment and we can decide together which is the most acceptable treatment for you. I think it is important that you are comfortable with the final decision."</i></p> <p><i>"It is important to be informed before you make a decision about treatment. Take some time to find out about the treatment options and what</i></p>	<p>DS (173, 193)</p> <p>QS (171, 172, 184, 192)</p>	<p>DS (168, 169)</p> <p>LR/G/T (53, 68, 159)</p>		

Key Communication Elements (DCIS)	Examples of communication	Evidence			
		DCIS women's experiences literature*	Communication literature*	DCIS diagnosis & management literature	Invasive breast cancer management literature
treatment	<i>the best course is for you."</i>				
v. Ask the woman for her preferred level of involvement in treatment decision-making. Ensure your understanding of the woman's preferences.	<i>"How do you feel about the different treatment options that I have discussed. How do you feel about having What are your concerns.....?"</i>				
vi. Offer the woman the opportunity for you to discuss treatment options with family members	<i>"You are welcome to bring your husband or other family members or friends into the consultation with me."</i> <i>"I am happy to discuss your diagnosis and treatment if any family member has any concerns or wants more information. My telephone number is"</i>				
4. Present the treatment options of breast conserving surgery, mastectomy, radiotherapy and hormonal therapies; and no treatment	<i>"Most women with DCIS are treated with breast conserving surgery with radiotherapy. Breast conserving surgery means that a woman's whole breast is not removed. Breast conserving surgery removes the area of DCIS plus a small area of healthy breast tissue around the DCIS (called the surgical margin). Breast conserving surgery is sometimes also called a lumpectomy."</i> <i>"However, in some circumstances, a woman may benefit more from a mastectomy. A woman may benefit more from a mastectomy if, for example.....Mastectomy removes a</i>	DS (173, 193) QS (171, 172, 184, 192)	I (78, 80) DS (129, 133, 137, 141, 149, 150, 168, 169) LR/G/T (53, 68, 159)	177-183, 186-191	

Key Communication Elements (DCIS)	Examples of communication	Evidence			
		DCIS women's experiences literature*	Communication literature*	DCIS diagnosis & management literature	Invasive breast cancer management literature
	<p>woman's whole breast, including the nipple.....”</p> <p>“Treatment after breast conserving surgery usually involves radiotherapy.....”</p>				
<p>5. Discuss the pros and cons of treatment options:</p> <p>i. Explain the aims/benefits and side effects of treatment(s)</p> <p>ii. Explain the features of a woman's DCIS which make her more or less likely to benefit from breast conserving surgery or mastectomy</p> <p>iii. Explain the features of a woman's DCIS which make her more or less likely to benefit from radiotherapy (ie the benefit of radiotherapy for women with small, low grade DCIS is less than for women with larger, higher grade DCIS)</p> <p>iv. Explain whether hormonal therapies may benefit women with DCIS (including the uncertainty); and the potential side effects of hormonal</p>	<p>“After a mastectomy you will usually have some pain, discomfort or numbness in your chest while the wounds are healing-this usually settles with time....”</p> <p>“How do you feel about having a mastectomy? What are your concerns....?”</p> <p>“Treatment after breast conserving surgery usually involves radiotherapy. Radiotherapy is not needed after a mastectomy. Radiotherapy uses X-rays (low doses of radiation) to destroy any abnormal cells that may be left in a woman's breast after surgery.”</p> <p>“Overall, radiotherapy decreases the risk of developing invasive breast cancer and DCIS by at least half.”</p> <p>“Radiotherapy benefits all women with DCIS. However, some women will benefit more from radiotherapy than other women. For example.....”</p>	<p>DS (173, 193)</p> <p>QS (171, 172, 184, 192)</p>	<p>I (78, 80)</p> <p>DS (129, 133, 137, 141, 149, 150, 168, 169)</p> <p>LR/G/T (53, 68, 159)</p>	<p>177-183,186-191, 221</p>	

Key Communication Elements (DCIS)	Examples of communication	Evidence			
		DCIS women's experiences literature*	Communication literature*	DCIS diagnosis & management literature	Invasive breast cancer management literature
therapies					
v. Explain the situations in which one or more lymph nodes may need to be removed	<i>"Hormonal treatments <u>may</u> decrease the risk of developing invasive breast cancer in both breasts. This is an area of current research. The possible benefits of hormonal treatments need to be weighed against the side effects for your situation....."</i>				
vi. Explain that chemotherapy is not used to treat DCIS	<i>"Chemotherapy is used in women with invasive breast cancer to kill any abnormal cells that may have spread in the body. <u>However</u>, chemotherapy is not used in the treatment of women with DCIS because the abnormal cells have not spread outside the milk ducts."</i>				
vii. Discuss the woman's values, preferences and concerns					
6. Explain the risk of DCIS and invasive breast cancer recurrence after treatment(s):	<i>"DCIS can usually be treated very successfully and most women diagnosed and treated for DCIS will not develop invasive breast cancer."</i>	DS (173-176)	I (78, 80) DS (129, 133, 137, 141, 149, 150, 168, 169)	177-183, 186-191	
i. Explain the risk of developing invasive breast cancer or DCIS after treatment (breast conserving surgery with or without radiotherapy for low and high risk groups; a mastectomy)	<i>"(use most recent data) Our best guess of the <u>overall</u> risk of developing invasive breast cancer in the same breast after breast conserving surgery <u>with</u> radiotherapy is about 8%. In other words, about 8 women out of 100 women will develop invasive breast cancer and 92 women won't develop invasive breast cancer. Whether you are one of the 9, I do not know. Our best guess of the <u>overall</u> risk of developing invasive breast cancer in the same breast after</i>		LR/G/T (18, 53, 68, 158, 159)		
ii. Use diagrams if available					
iii. Tailor information to the individuals'					

Key Communication Elements (DCIS)	Examples of communication	Evidence			
		DCIS women's experiences literature*	Communication literature*	DCIS diagnosis & management literature	Invasive breast cancer management literature
characteristics where possible	<p><i>breast conserving surgery <u>without</u> radiotherapy is about 13%. In other words, about 13 out of 100 women will develop invasive breast cancer and 87 women won't develop invasive breast cancer. Whether you are one of the 13, I do not know.</i></p> <p><i>After a mastectomy for DCIS, our best guess of the risk of developing invasive breast cancer in the small breast tissue that is left is less than 1%. In other words, after mastectomy, 1 woman out of <u>200</u> women will develop invasive breast cancer. Whether you are the one woman, I do not know."</i></p>				
7. Discuss your treatment recommendation(s)	<p><i>"I'm here to advise you about possible treatment options, and then we can discuss together what would be best for you. I'll tell you what I think, and then you have time to think about this yourself."</i></p>		DS (168, 169) LR/G/T (53, 68)		
8. Offer the opportunity to delay treatment decision(s) and arrange follow-up to discuss treatment decision(s)	<p><i>"There is no need to rush to make a decision about treatment. Take some time to find out about the treatment options and what the best course is for you."</i></p> <p><i>"We don't need to decide anything today. Have a think about what we have discussed and come</i></p>		DS (168, 169) LR/G/T (53, 68)		

Key Communication Elements (DCIS)	Examples of communication	Evidence			
		DCIS women's experiences literature*	Communication literature*	DCIS diagnosis & management literature	Invasive breast cancer management literature
	<p><i>back and see me next week. We can then decide on the best treatment plan for you."</i></p> <p><i>"If you think of things at home you would like to ask me just write them down and bring them next time, okay?"</i></p>				
9. Discuss any physical symptoms with the woman related to her treatment and how to manage them	<p><i>"How is the wound feeling after your mastectomy? Do you have any pain or discomfort?"</i></p> <p><i>"Each woman is different in how long she takes to recover from surgery....."</i></p> <p><i>"How are you finding the prosthesis? Is it comfortable for you?....."</i></p> <p><i>"Where possible after radiotherapy, keep your skin clean and dry, and use mild unperfumed soaps or a glycerin based mild cream....."</i></p> <p><i>"Some women find that they feel more tired after radiotherapy. How are you feeling?"</i></p>	<p>DS (176, 175, 195, 199)</p> <p>QS (172)</p>	<p>I (78, 80)</p> <p>LR/G/T (1)</p>	177-183, 186-191	
10. Sensitively discuss sexual and body image issues during treatment decision-making and after treatment: Follow the woman's cues for privacy or disclosure	<p><i>"I know this might be difficult to discuss, but the diagnosis and treatment of DCIS may affect how women feel about their body and their relationships. Can you tell if there are any things like that that are worrying you?"</i></p>	<p>DS (175, 193, 199)</p> <p>QS (172)</p>	LR/G/T (1)		197, 198

Key Communication Elements (DCIS)	Examples of communication	Evidence			
		DCIS women's experiences literature*	Communication literature*	DCIS diagnosis & management literature	Invasive breast cancer management literature
	<p><i>"Although it is often hard to talk about, many women feel concerned about how they will look and feel about their bodies after treatment. How do you feel about this?"</i></p> <p><i>"Are there specific things that cause you particular concern?"</i></p> <p><i>"Have you discussed any of these concerns with your partner?"</i></p>				
11. Discuss physical activity after treatment: Discuss the benefits of physical activity and the reasons for any physical inactivity	<p><i>"Some women find that they are less active after being diagnosed and treated for DCIS. Are you finding this?.....Do you do any exercise regularly?.....Has this changed as a result of the diagnosis and treatment?....."</i></p> <p><i>"I know it is hard to exercise when you feel tired. But exercising can actually make you feel less tired and help you feel better in yourself. What exercise do you enjoy.....walking...swimming...."</i></p> <p><i>"It sounds like you have been taking good care of yourself after treatment."</i></p>	DS (202, 207, 208)			201-208

Key Communication Elements (DCIS)	Examples of communication	Evidence			
		DCIS women's experiences literature*	Communication literature*	DCIS diagnosis & management literature	Invasive breast cancer management literature
D. Effectively providing information to women with DCIS					
1. Tell the woman the most important information first, that is, that she does not have invasive breast cancer	"The good news is you do not have breast cancer as we commonly understand it.		LR/G/T (113, 120)		
2. Use diagrams			I (46, 119) LR/G/T (1, 118)		
3. Check the woman's understanding of her diagnosis, prognosis and treatment and clarify any misunderstanding	"I just want to make sure that I have communicated clearly. Tell me what you understand about your diagnosis from what I have said so far?"		DS (110) LR/G/T (107, 109)		
4. Invite questions	"Do you want to ask me any questions?" "Are you unsure about anything I have said?"		DS (114, 115) LR/G/T (1, 2)		
5. Respond to the woman's cues (indirect statements) for information	Woman: "I really don't know much about the different treatment." HP: "There are several options for treatment. Firstly, breast conserving surgery which means...."		DS (124, 125)		
6. Summarise and repeat information	"Can I just repeat what I've said so far. There are three options...."	DS (173)	DS (53) LR/G/T (104, 107)		

Key Communication Elements (DCIS)	Examples of communication	Evidence			
		DCIS women's experiences literature*	Communication literature*	DCIS diagnosis & management literature	Invasive breast cancer management literature
7. Tailor information to the woman's needs and characteristics where possible			LR/G/T (156-158)		
8. Provide the woman with written information about the diagnosis, prognosis, and treatment and support services available to her: Include information about appropriate websites		DS (173) QS (172)	DS (53, 142, 145)		
<i>E. Effectively providing support for women with DCIS</i>					
1. Respond to emotion:					
A. Allow and encourage the woman to express her concerns and feelings: Ask open questions, listen carefully, acknowledge concerns and feelings, clarify concerns and feelings	<i>"It must be a lot to deal with. How do you feel about it all so far?"</i> <i>"What concerns you most about your diagnosis?"</i> <i>"What has been the most difficult about this diagnosis for you?"</i>	DS (173, 176, 193, 195) QS (171, 172, 184)	I (98, 210) DS (123-125, 209) LR/G/T (1, 2, 122)		
B. Respond with empathy: Acknowledge, normalise and validate the woman's concerns and feelings	<i>"Many women feel sad and worried about things after a diagnosis of DCIS. How are you feeling about all of this?"</i>				
C. Assess and respond to anxiety and depression: Refer to a psycho-social health professional (counsellor, psychologist or	<i>"It's not uncommon to feel this way at a time like this."</i> <i>"It's understandable that you are feeling</i>				

Key Communication Elements (DCIS)	Examples of communication	Evidence			
		DCIS women's experiences literature*	Communication literature*	DCIS diagnosis & management literature	Invasive breast cancer management literature
psychiatrist) if appropriate	<i>anxious. What in particular are you worried about"</i> <i>"Yes, it is very hard."</i> <i>"People often do....."</i> <i>"I understand....."</i> <i>"Yes..",</i> <i>"Hm..."</i>				
2. Avoid minimising the impact of the diagnosis and treatment of DCIS.	<i>"Many women with DCIS find that coping with the diagnosis and treatment is often very stressful. It is common for women to feel shocked, sad and worried about things. How do you feel about it all so far?"</i> <i>"It's not uncommon to feel this way at a time like this."</i> <i>"It's understandable that you are feeling anxious."</i>	QS (172)	I (98, 210) DS (125) LR/G/T (122)		
3. Acknowledge and help manage uncertainty:	<i>"How are you feeling about your diagnosis now?....."</i>	DS (173)	I (78-80, 82)	177-183, 186-191	
i. Acknowledge and discuss the diagnostic, prognostic and treatment	<i>"It is understandable that you have concerns about the future. However, I'd like to reassure you though that most women diagnosed and</i>	QS (171, 172, 184)	DS (72) LR/G/T (4-7)		

Key Communication Elements (DCIS)	Examples of communication	Evidence			
		DCIS women's experiences literature*	Communication literature*	DCIS diagnosis & management literature	Invasive breast cancer management literature
<p>uncertainties of DCIS</p> <p>ii. Provide verbal and written information about what is currently known about the diagnosis, prognosis, and treatment of DCIS, including treatment side effects and how to manage them</p> <p>iii. Identify any areas of concern for the individual woman, assisting with problem-solving and providing information where available</p> <p>iv. Enable the woman's positive reappraisal of the meaning of the diagnosis, for example, "this diagnosis does not signal death" by reassuring the woman of a good prognosis</p> <p>v. Allow and encourage the woman to express her concerns and feelings about any areas of uncertainty (for example, uncertainty related to the diagnosis, prognosis, treatment side effects and how to manage them; triggers of fear of recurrence at annual mammograms; and having unexplained symptoms) and</p>	<p><i>treated for DCIS will not have any further problems. And regular check-ups will ensure that we detect any early problems."</i></p> <p><i>"The good news is that DCIS can be treated very successfully and most women diagnosed and treated for DCIS will not have any further problems."</i></p> <p><i>"Do you often worry about your diagnosis and the future?.....Do you often worry about getting cancer?... How do these worrying thoughts affect your life? Are they interfering with your normal activities or your sleep?...Does any situation triggers these feelings of worry?.... "</i></p> <p><i>"Is there anything that you would like more information about?.... Are you having any side effects to the treatment such as soreness, fatigue etc..."</i></p> <p><i>"Sharing your thoughts and feelings with your family and friends can help you to cope. Is there someone that you can talk to about how you are feeling or what you may be worried about?"</i></p>				

Key Communication Elements (DCIS)	Examples of communication	Evidence			
		DCIS women's experiences literature*	Communication literature*	DCIS diagnosis & management literature	Invasive breast cancer management literature
	respond with empathy by acknowledging, normalising and validating the woman's concerns and feelings about uncertainty				
vi.	Encourage the woman to utilise her social support system				
4.	Assess the woman's level of support from a partner, family, friends and social support networks	<p><i>"Sharing your thoughts and feelings with your family and friends can help you to cope. Is there someone that you can talk to about how you are feeling or what you may be worried about?"</i></p> <p><i>"[If woman has partner and a family] A diagnosis of DCIS is often stressful for the family. Can you tell me how things are at home? How are your partner and family handling it?"</i></p> <p><i>"Are you involved in any community groups or religious groups or clubs? Hasbeen a support for you during this time?"</i></p>	<p>DS (174, 175, 195)</p> <p>QS (172)</p>	<p>DS (72, 95)</p> <p>LR/G/T (1, 2)</p>	
5.	Provide information about support groups and services: DCIS specific and invasive breast cancer support groups (including professionally-run support groups, peer support groups, telephone and Internet	<p><i>"For many women it is very useful to join a support group. A support group holds regular meetings for people to talk about their experiences with other people in similar situations. There is a support group for women with DCIS. So if you're interested here is a</i></p>	<p>Q (171, 172)</p>	<p>I (215-218)</p> <p>LR/G/T (1, 2)</p>	

Key Communication Elements (DCIS)	Examples of communication	Evidence			
		DCIS women's experiences literature*	Communication literature*	DCIS diagnosis & management literature	Invasive breast cancer management literature
support groups), the Breast Cancer Support Service (BCSS), and local cancer organisations	<p><i>pamphlet.</i> ”</p> <p><i>“For many women it is very useful to join a support group. There is a support group for women with invasive breast cancer and DCIS. Women with invasive breast cancer will have similar treatments to women with DCIS. However, you must remember that DCIS is quite different from invasive breast cancer..... I have here a pamphlet.</i> ”</p>				
F. Effectively providing information and support for women with DCIS from culturally and linguistically diverse (CALD) backgrounds (in addition to the Key Communication Elements (DCIS) above)					
1. Be sensitive to the woman's cultural background: Be aware that the meaning of the diagnosis and treatment for the woman will be affected by her ethnic and religious background		QS (192, 219)	I (97) LR/G/T (1, 2, 109)		
2. Effectively provide information:					
i. Use diagrams	<p><i>“I just want to make sure that I have communicated clearly the type of breast disease you have. How do you understand the difference between your breast disease and breast cancer as we commonly think of it?”</i></p>	QS (192, 219)	I (97) LR/G/T (1, 2, 109)		
ii. Check the woman's understanding of her diagnosis, prognosis and treatment and clarify any misunderstanding					

Key Communication Elements (DCIS)	Examples of communication	Evidence			
		DCIS women's experiences literature*	Communication literature*	DCIS diagnosis & management literature	Invasive breast cancer management literature
iii. Provide the woman with written information about the diagnosis, treatment and support services in the woman's first language if available					
3. If the woman is not proficient in English, suggest and arrange a professional interpreter: Explain the role of the interpreter and ensure woman agrees to interpreter's presence	<i>"A professional interpreter can make sure that you understand everything I say. It may be hard for family members or friends to interpret all things I say including the medical terms. We can arrange for a professional interpreter to be with you during the consultation with me and we could discuss further your diagnosis and treatment. Would you like this to be arranged?"</i>	QS (192, 219)	I (97) LR/G/T (1, 2, 109)		
4. Involve the woman in treatment decision-making:					
i. Discuss the woman's values, preferences and concerns about treatment	<i>"There are several options for treatment and we can decide together what is the most acceptable treatment for you. I think it is important that you are comfortable with the final decision."</i> <i>"I am happy to discuss your treatment options with your husband or other family members."</i>	QS (192, 219)	I (97) LR/G/T (1, 2, 109)		
ii. Be aware that family members of women with DCIS from culturally and linguistically diverse (CALD) backgrounds may play an important role in treatment decision-making and involve them in consultations or by	<i>"You are welcome to bring your husband or other family members into the consultation with me."</i> <i>"I am happy to discuss your diagnosis and treatment if any family member has any</i>				

Key Communication Elements (DCIS)	Examples of communication	Evidence			
		DCIS women's experiences literature*	Communication literature*	DCIS diagnosis & management literature	Invasive breast cancer management literature
	<p>telephone where possible</p> <p><i>concerns or wants more information. My telephone number is".</i></p> <p><i>"It is important to be informed before you make a decision about treatment. Take some time to find out about the treatment options and what the best course is for you."</i></p>				
<p>5. Respond to emotion:</p> <p>i. Allow and encourage the woman to express her concerns and feelings about her diagnosis, prognosis and treatment and respond with empathy</p> <p>ii. Be aware that how the woman feels about her diagnosis and treatment will be affected by her ethnic and religious background</p> <p>iii. Refer the woman to a psycho-social health professional (if appropriate) who is sensitive to the woman's ethnic and religious background</p>	<p><i>"I am here to find out not just about the physical effects of treatment but how you are feeling."</i></p> <p><i>"What concerns you most about your diagnosis?"</i></p> <p><i>"Many women feel sad and worried about things after a diagnosis of DCIS. How are you feeling about all of this?"</i></p> <p><i>"For more information and support you may also call [telephone service for women who speak.....(language)]."</i></p> <p><i>"I think it would be helpful if you talked with someone about how you are feeling. There is a very good person that I know who speaks (language)...."</i></p>	<p>QS (192, 219)</p>	<p>LR/G/T (1, 2)</p>		

Key Communication Elements (DCIS)	Examples of communication	Evidence			
		DCIS women's experiences literature*	Communication literature*	DCIS diagnosis & management literature	Invasive breast cancer management literature
6. Assess the woman's level of support from a partner, family, friends and social support networks: Be aware that ethnic and religious organisations may offer the woman important support	<p><i>"Sharing your thoughts and feelings with your family and friends can help you to cope. Is there someone that you can talk to about how you are feeling or what you may be worried about?"</i></p> <p><i>"[If woman has partner and family] A diagnosis of DCIS is often stressful for the family. Can you tell me how things are at home? How are your partner and family handling it?"</i></p> <p><i>"[If woman has a partner] Can you tell me how things are at home? Are you feeling that you are getting the emotional support you need?"</i></p> <p><i>"Are you involved in any community groups or religious groups or clubs? Hasbeen a support for you during this time?"</i></p>	QS (192, 219)	LR/G/T (1, 2)		
7. Provide information about support groups and services in woman's first language if available	<p><i>"For more information and support you may also call [telephone service for women who speak.....(language)]."</i></p> <p><i>"There is a support group for women with invasive breast cancer and DCIS who speak.....(language). I have here a pamphlet about the support group."</i></p>	QS (192, 219)	LR/G/T (1, 2)		

*Key: **I** Intervention study **DS** Quantitative descriptive study **QS** Qualitative study **LR/G/T** Literature review of descriptive studies; Guidelines; or Theory

4 Discussion

There is confusion and misunderstanding among women diagnosed with DCIS about *how* their disease differs from invasive breast cancer and a desire for more information about important aspects of their diagnosis and treatment. Women diagnosed with DCIS have been shown to experience unnecessary distress due to their lack of understanding about DCIS. Furthermore, women diagnosed with DCIS must cope with various diagnostic, prognostic and treatment uncertainties in addition to the uncertainties inherent in the experience of illness. Good communication is essential to promote better understanding about DCIS and increase the well-being of women with DCIS.

To date, there are no comprehensive evidence-based recommendations for clinicians that address the communication challenges specific to DCIS. Thus, the *Key communication elements for effectively communicating with women diagnosed with ductal carcinoma in situ (DCIS)* were developed to address this need. This chapter describes the first stage of development of recommendations for clinicians about communicating with women diagnosed with DCIS. The *Key Communication Elements (DCIS)* are based on a systematic review of the experiences of women diagnosed with DCIS described in *Chapter 1* and a cross-sectional survey of Australian women with DCIS described in *Chapter 2*. It is acknowledged that the evidence concerning the experiences of women with DCIS is limited to descriptive studies (including observational studies and qualitative studies) and that there is currently no evidence of the effectiveness of the proposed recommendations with women with DCIS. Therefore, the *Key Communication Elements (DCIS)* cannot yet be considered the ‘gold standard’ for communication about DCIS. It is expected that the *Key Communication Elements (DCIS)* will be further refined as new evidence comes to light, particularly from studies evaluating communication interventions with women diagnosed with DCIS.

The initial piloting of the *Key Communication Elements (DCIS)* is limited by the small and select sample of clinicians and health researchers and the absence of women diagnosed with DCIS. However, it was beyond the scope of this thesis to conduct further stages

required to develop rigorous evidence-based clinical practice guidelines such as establishing a multidisciplinary group of women with DCIS, clinicians, and researchers to oversee the development of the recommendations and review the evidence supporting the recommendations; and conducting an extensive public consultation process involving members of the relevant professions and women with DCIS.¹⁷⁰ Further stages of development of the recommendations are required to ensure that the needs of women with DCIS are addressed and that the recommendations are acceptable, appropriate and practical for clinicians in their consultations with women.

The *Key Communication Elements (DCIS)* are intended to guide clinicians in their consultations with women diagnosed with DCIS (including the initial diagnostic consultation and subsequent consultations concerning treatment and follow-up). However, it is acknowledged that medical care is frequently delivered by a multidisciplinary team and it is important that there is a continuity of communication among team members.¹²⁸ Therefore, the *Key Communication Elements (DCIS)* could be further developed and tested to ensure their appropriateness to all members of the multidisciplinary team who care for women diagnosed with DCIS.

The *Key Communication Elements (DCIS)* provide some guidance for clinicians about how to communicate with women diagnosed with DCIS from culturally and linguistically diverse (CALD) backgrounds. Given the paucity of evidence about the experiences of Australian Aboriginal or Torres Strait Islander women with DCIS, the *Key Communication Elements (DCIS)* do not address their concerns and needs. Further research is needed to explore the experiences of Australian Aboriginal women with DCIS and women with DCIS from other CALD backgrounds.

4.1 Practice implications

The *Key Communication Elements (DCIS)* could be further developed and disseminated as clinical practice guidelines for clinicians about how to communicate about DCIS to women. There is evidence that clinical practice guidelines can be effective in changing the process

of care and health outcomes.²²² However, there is also evidence that guidelines alone will not improve care.²²² An effective strategy for implementing the recommendations in the *Key Communication Elements (DCIS)* may be to incorporate them into communication skills training programs for clinicians about how to communicate effectively about DCIS.^{2,222} There is evidence that communication skills training programs can improve doctors' communication skills, increase doctors' confidence in communicating effectively with patients, and change doctors' attitudes about the importance of psychosocial issues and communicating well.³ The essential characteristics of communication skills training programs are the provision of a cognitive component or evidence base for suggested skills, a behavioural component allowing participants to rehearse the actual communication skills required through role play with patient actors, and an effective component permitting participants to explore the feelings that communicating about various issues evoke.¹²⁸

Another effective strategy for implementing the *Key Communication Elements (DCIS)* may be to develop decision aids and communication aids based on the *Key Communication Elements (DCIS)* for doctors to use with women with DCIS during their consultations. Decision aids⁴⁶ and communication aids^{118,119,223} have been shown to improve doctor-patient communication, improve patients' understanding and recall of information, reduce patients' difficulty with decision-making, and increase patients' participation in the decision-making process.

4.2 Conclusions

This chapter describes the first stage of development of recommendations for clinicians about how to effectively communicate with women diagnosed with DCIS. The strength of the *Key Communication Elements (DCIS)* is firstly, that they are based on the best available evidence; secondly, they provide clinicians with clear recommendations about how to effectively communicate about DCIS including examples of clinician communication; thirdly, their comprehensive nature with recommendations covering key aspects of the diagnosis, prognosis, treatment and support of women with DCIS; and fourthly, they address the uncertainties related to the diagnosis, prognosis and treatment of DCIS.

Further stages of development of the recommendations are required to ensure their appropriateness for women with DCIS, clinicians, and other health professionals involved in the care of women with DCIS. Implementation of these recommendations has the potential to improve doctor-patient communication about DCIS and increase the well-being and health outcomes of women with DCIS.

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Chapter 4

“Well, have I got cancer or haven’t I?” How well do doctors communicate a diagnosis of ductal carcinoma in situ (DCIS) with women: opportunities for improving practice

1 Introduction

DCIS is an increasingly common diagnosis in women since the advent of widespread breast screening mammography.¹ There are unique communication challenges associated with a diagnosis of DCIS arising from the fact that DCIS is not an invasive cancer and does not have the capacity to spread and cause death² and that uncertainty exists about whether a particular woman's DCIS will progress to invasive breast cancer or the time interval in which invasive breast cancer will occur if left untreated.³

Chapter 1 and Chapter 2 demonstrate that there is evidence that women with DCIS are confused about their diagnosis and do not understand how their diagnosis differs from invasive breast cancer. Poor knowledge about DCIS has been associated with higher levels of anxiety and cancer specific worry among women with DCIS. Women with DCIS also report that they want more information about important aspects of their diagnosis and prognosis.

Doctor-patient communication about DCIS is likely to be very important in determining how women with DCIS understand their diagnosis. However, no published study to date has examined how doctors *actually* communicate about DCIS to women. The objective of this study was to begin to develop an understanding of how doctors communicate with women with DCIS using the *Key Communication Elements (DCIS)* developed in *Chapter 3* to structure the analysis. The *Key Communication Elements (DCIS)* aim to assist doctors to effectively communicate about DCIS. They are based on the best available evidence from the literature concerning the experiences of women diagnosed with DCIS (limited to descriptive studies) and the literature about doctor-patient communication (including descriptive and intervention studies largely with cancer patients).

Understanding how doctors communicate about DCIS could provide vital information to guide future interventions to improve communication and women's understanding about DCIS and decrease the distress associated with the diagnosis. The present study uses direct observation technique and provides an indepth description of doctor-patient communication about DCIS by examining audio-taped initial diagnostic consultations

(n=30) with surgeons (n=13) and women with DCIS at BreastScreen centres (government funded mammographic screening centres) in Victoria, Australia.

Audio-taping consultations between doctors and patients has been shown to be a valuable research tool, contributing to understanding doctor-patient communication in many contexts including studying whether informed decision-making exists in practice;⁴ how doctors consent patients for clinical trials;⁵ how doctors disclose uncertainty;⁶ whether doctors provide patient-centred care;⁷ how doctors provide reassurance and hope to cancer patients;⁸ shared decision-making in oncology consultations;⁹ doctors' responses to emotional and informational cues from patients;¹⁰ and the effect of interventions such as a pre-consultation question prompt sheet¹¹ and patient question-asking.¹² An important advantage of audio-tapes over participant reports is their reliability; reports of events from patients often differ from actual occurrences.¹³ Although audio-tapes cannot be used to analyse non-verbal communication, they are less costly and may be less intrusive and more acceptable to clinicians and patients than video-taping.¹³

Communication between doctors and patients has been analysed using various methods including interaction analysis systems (IAS)¹⁴ such as Roter's Interaction Analysis System (RIAS),¹⁵ the Medical Interaction Process System (MIPS),¹⁶ the Cancode interaction analysis system (developed from CN-LOGIT),⁷ and the Decision Analysis System for Oncology (DAS-O) which analyses shared decision-making;⁹ cross-sectional analyses of doctors' communication and patient cues and concerns;^{10,17} conversational analysis¹⁸ and sequence analysis^{19,20} (which analyses the patterns of interaction between doctors and patients and the effect of one individual's speech on the other's speech); and qualitative analyses.²¹

As no single method can model the complexity of clinical communication, researchers have suggested using multiple methods, including quantitative and qualitative techniques, to analyse communication between doctors and patients.^{17,19,22} Given the complexity of DCIS and the need for a deeper understanding of doctor-patient communication about DCIS, the present study uses both quantitative and qualitative methods to examine the communication in the consultations.

The specific aims of this study are to describe 1) how and to what extent surgeons communicate in accord with the *Key Communication Elements (DCIS)* in the initial diagnostic consultation; 2) the key terms and phrases surgeons use to describe DCIS and invasive breast cancer; 3) the differences between surgeons in their communication about DCIS; and 4) whether surgeons communicate about DCIS in the same way to different women, and the possible factors contributing to any variation in communication.

2 Methods

2.1 Setting

The present study examined the communication of the diagnosis and prognosis of DCIS during audio-taped initial diagnostic consultations at two urban BreastScreen assessment centres in Melbourne, Victoria. BreastScreen Australia was the most appropriate organisation for recruitment of women to the study as more than half of DCIS diagnoses occur within BreastScreen Australia.²³ BreastScreen Australia provides free mammography to asymptomatic women through an organised screening service incorporating recruitment and recall for screening every two years. BreastScreen is targeted to women aged 50-69 years. BreastScreen Australia has a mammographic screening program in each state funded by the relevant state governments. There are several BreastScreen assessment centres in Victoria, including urban and rural services. Two services in Melbourne were approached for their willingness to participate in the study, St Vincent's BreastScreen and Monash BreastScreen. The number of surgeons from these services was considered adequate to provide an indepth description of the communication about DCIS.

2.2 Development of study design and procedures

The methodology and recruitment procedures for the study were developed through consultation with BreastCare Victoria and BreastScreen Victoria to ensure that no additional distress was caused to women at the time of their diagnosis with DCIS, that

the study procedures were understood, and that the study was adapted to the clinical practices at the BreastScreen assessment centres and had the support of the directors and staff each centre. The consultation process included the following steps:

- The aims, methodology, and feasibility of the study were initially discussed with BreastCare Victoria.
- The initial diagnostic (biopsy result) consultation was identified as the most important consultation for data collection because the consultation is primarily concerned with explaining the diagnosis of DCIS. *Figure 1 (see Page 273)* highlights the diagnostic and treatment pathway for women who are diagnosed with DCIS at BreastScreen assessment centres.
- The methodology, feasibility and ethical considerations for the study were discussed during meetings with the BreastScreen Victoria Research and Evaluation Committee (R&EC). The R&EC includes cancer researchers, a surgeon, and women diagnosed with invasive breast cancer, ductal carcinoma in situ (DCIS) and lobular carcinoma in situ (LCIS). The study proposal was approved by the R&EC.
- The methodology of the study was discussed with the directors of St Vincent's BreastScreen and Monash BreastScreen to gain their consent to participate in the study and ensure that the clinic procedures were understood at the BreastScreen services.
- The study was discussed with surgeons, radiologists, nurses and counsellors at the BreastScreen services and the research nurse employed for the study to ensure that they were fully informed about the aims, methodology and recruiting procedures for the study and that all their concerns were addressed.
- All counsellors and nurses from the BreastScreen assessment centres received an information package about the study which included a protocol for counsellors or nurses providing step by step instructions about their role in the study (*see Appendix 4.1*).

- The research nurse received an information package which included a protocol providing step by step instructions about her role in the study and how to code the audio-tapes (*see Appendix 4.2*); a refusal form to record the number of women who did not consent to the study and the reasons for not consenting (*see Appendix 4.3*); a coding log form to record the names and codes (on the audio-tapes) of consenting women (*see Appendix 4.4*); a coding log form to record the names and codes (on the audio-tapes) of surgeons and how many consultations the surgeon had audio-taped (*see Appendix 4.5*).
- All surgeons from the BreastScreen assessment centres received an information package about the study which included information (*see Appendix 4.6*) about the background and aims of the study, the study methodology, ethical guidelines and contact numbers for any concerns or complaints about the study; a consent form for surgeons (*see Appendix 4.7*); a brief survey of surgeons' age and practice characteristics (*see Appendix 4.8*); a protocol for surgeons providing step by step instructions about their role in the study (*see Appendix 4.9*); and a comment sheet for surgeons to make any additional comments about an individual audio-taped consultation (*see Appendix 4.10*).

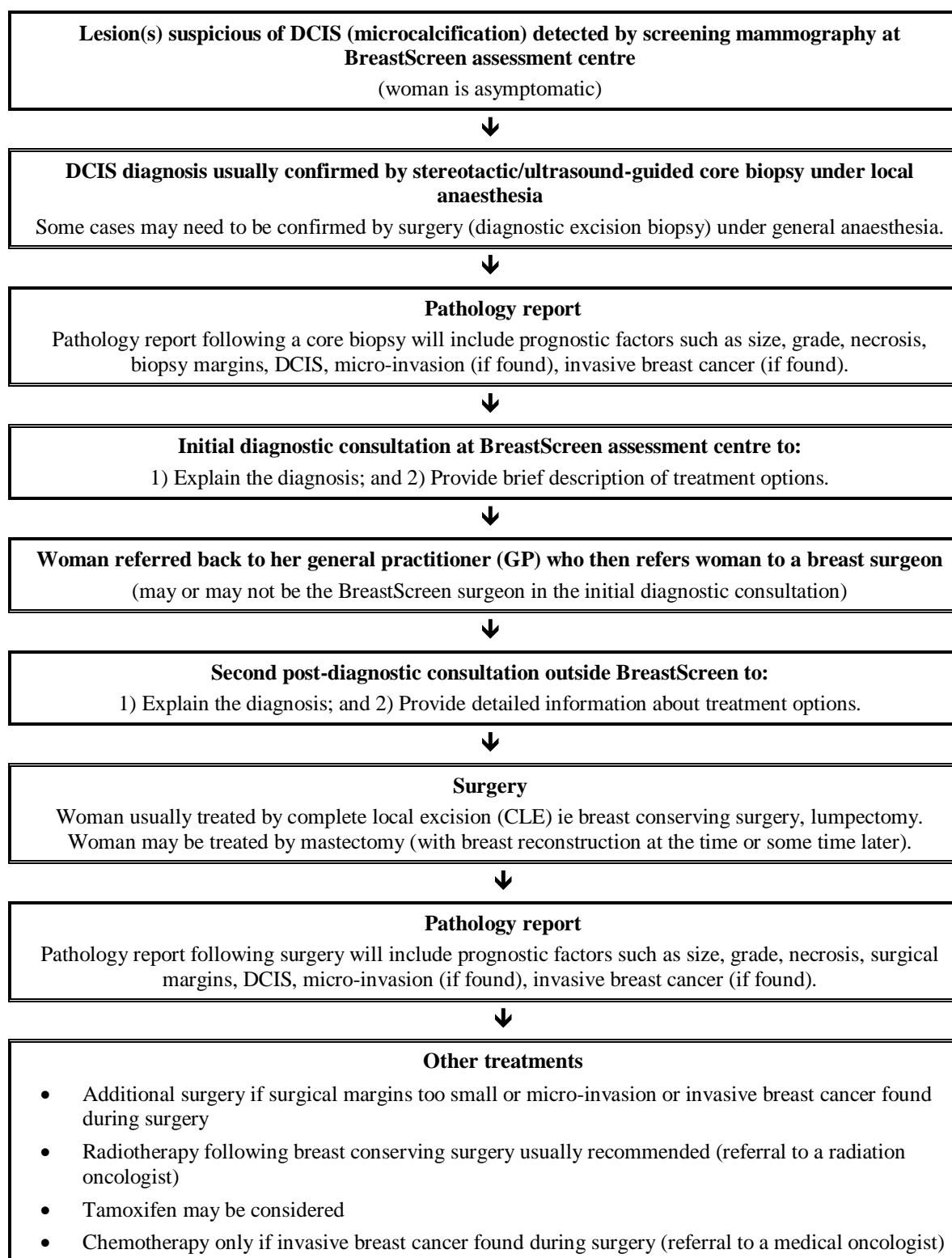
2.3 Ethics approval for the study

Approval to conduct the study was granted by The Cancer Council Victoria Human Research Ethics Committee and the ethics committees for the two BreastScreen services, that is, St Vincent's Hospital Melbourne Human Research Ethics Committee (for St Vincent's BreastScreen and St Vincent's Hospital) and Southern Health Human Research Ethics (for Monash BreastScreen and Monash Medical Centre).

2.4 Funding

The study was funded by BreastCare Victoria and the National Breast and Ovarian Cancer Centre (NBOCC), Sydney, Australia

Figure 1: Diagnostic and treatment pathway for women involved in the study*



* Information obtained from the directors of the BreastScreen assessment centres involved in the study

2.5 Study population

2.5.1 *Women diagnosed with DCIS*

Women were eligible to participate in the study if they had a biopsy result indicating that they had DCIS. As BreastScreen only assesses women who have not previously had a breast problem, none of the women in the study had a previous diagnosis of invasive breast cancer or DCIS.

Women were excluded if they:

- were deemed by the BreastScreen counsellors or nurses to be too psychologically unwell to participate in the study
- required a professional language interpreter to be present during the consultation
- were hearing impaired and required a professional interpreter to be present during the consultation
- were women living in rural or remote areas and would be receiving their results from their general practitioner
- had a simultaneous diagnosis of invasive breast cancer

2.5.2 *Surgeons*

Surgeons were eligible to participate in the study if they consulted with eligible women during the initial diagnostic (biopsy result) consultation at St Vincent's BreastScreen or Monash BreastScreen.

2.6 Recruitment and participation of women diagnosed with DCIS

2.6.1 *Recruitment of women diagnosed with DCIS*

Stage 1: BreastScreen counsellors (at St Vincent's BreastScreen) and BreastScreen nurses (at Monash BreastScreen) initially explained the purpose of the study to all women who had *lesions suspicious of DCIS* at the time of their biopsy. Women were

also given an information sheet about the study at that time (*see Appendix 4.11*). Eligibility for lesions suspicious of DCIS was determined by the radiologist at the BreastScreen assessment centre.

Stage 2: The radiologists and surgeons at the BreastScreen assessment centre were informed about which women had DCIS from the pathology reports of biopsied suspicious lesions. A research nurse approached women who had DCIS at the time of their biopsy-result consultation with a surgeon for their consent to participating in the study. Consenting women completed a demographic survey (*see Appendix 4.12*) and signed a consent form (*see Appendix 4.13*).

2.6.2 *Participation of women diagnosed with DCIS*

One hundred and forty women who had lesions suspicious of DCIS received an information sheet during the eleven month study period (May 2003 to April 2004). Twenty-six women were excluded from the study for the following reasons: women from culturally and linguistically diverse (CALD) backgrounds requiring a professional interpreter (n=9); women living in rural or remote areas receiving their results from their general practitioner (n=16); and a hearing-impaired woman requiring a professional interpreter (n=1). Although women were not asked for their consent when they initially received an information sheet about the study, 11 women refused to participate at this time. Five women did not want to be audio-taped and there was no reason recorded for six women.

Of the 103 women who were provided with initial information and were willing to be further approached about the study, 52 women were diagnosed with DCIS and 51 women were diagnosed with invasive breast cancer or benign breast conditions. The research nurse was unable to approach 19 women diagnosed with DCIS for consent to participating in the study for the following reasons: the research nurse received the results too late to travel to the BreastScreen assessment centre on the day the women received their results (n=6), the research nurse was unable to attend on the day the women received their results (n=5), the research nurse was attending the other BreastScreen assessment centre on the day the woman received her results (n=1), the

surgeon had already audio-taped three DCIS consultations (n=6), and the radiologist gave the results to the woman as there were no surgeons available to give the results on the day the woman received her results (n=1).

The research nurse therefore approached 33 women diagnosed with DCIS from the BreastScreen assessment centres for their consent to participate in the study. Thirty-one women consented with two women refusing to participate in the study because they did not want the consultation to be audio-taped (*consent rate=94%*). An audio-taped consultation with one woman diagnosed with DCIS was not included in the analysis as there was no recording on the audio-tape until nine minutes into the consultation. Therefore, 30 audio-taped consultations with women diagnosed with DCIS were included in the analysis.

For ethical reasons, women participating in the study were given a copy of their audio tape immediately after their consultation. A Cochrane systematic review of cancer patients who receive audio tapes of their consultation found that most patients thought the audio-tape was valuable, and increased patients' recall of the information in the consultation and their satisfaction with the information they received.²⁴

2.7 Recruitment and participation of surgeons

All eligible surgeons (n=21) including ten surgeons from St Vincent's BreastScreen and eleven surgeons from Monash BreastScreen, provided written consent to participate in the study (*consent rate=100%*). Surgeons were instructed to audio-tape up to three consultations with eligible women within the study period. However, due to the low numbers of DCIS diagnosed at BreastScreen services compared to invasive breast cancer during the study period, and the particular consulting days of the individual surgeons, only thirteen surgeons, including three surgeons from St Vincent's BreastScreen and ten surgeons from Monash BreastScreen, were able to participate in the study (*Participation rate=62%*).

2.8 Sample size

The study aimed to provide an indepth description of doctor-patient communication about DCIS. The sample size of thirteen surgeons and thirty women diagnosed with DCIS was considered adequate to enable data saturation (no new ways to communicate information in three consecutive consultations), and for the findings to be transferable to surgeons and women diagnosed with DCIS with similar characteristics in similar contexts.

2.9 Data analysis

Quantitative and qualitative analyses were used to examine doctor-patient communication about DCIS. A coding manual was developed for the analysis (see *Appendix 4.14* for the coding manual and see *Section 2.9B* for a description of the development of the coding manual). The consultations were audio-taped and transcribed verbatim.

2.9A Selection of relevant Key Communication Elements (DCIS)

This study aimed to examine how and to what extent surgeons communicate in accord with the *Key Communication Elements (DCIS)* in the initial diagnostic consultation. Ten *Key Communication Elements (DCIS)* relevant to the initial diagnostic consultation were selected for inclusion in this study. Given that the purpose of the initial diagnostic consultation is to explain the diagnosis of DCIS to women, the selected *Key Communication Elements (DCIS)* focused on initial explanations of the diagnosis and natural history of DCIS and reassurance of women, and not on communication tasks likely to occur in subsequent consultations, such as effectively communicating about treatment, follow-up and support. Thus, information-giving behaviours and communication behaviours to facilitate understanding of the information provided to women were included while women's involvement in treatment decision-making, and whether clinicians elicited and responded to emotion and referred women to support services were not included, as highlighted in *Table 4.1*.

Table 4.1: Selected Key Communication Elements (DCIS) included in this study

Key Communication Elements (DCIS)	
<i>Information-giving behaviours</i>	
1	Reassure the woman that she <u>does not</u> have invasive breast cancer
2	Tell the woman she has ductal carcinoma in situ or DCIS
3	Explain how DCIS differs from invasive breast cancer
4	Explain the natural history of DCIS including the uncertainty
5	Explain the provisional nature of prognostic information
6	Explain the aim and importance of treatment
7	Reassure the woman of an excellent prognosis after treatment
<i>Communication behaviours: Facilitating understanding</i>	
8	Use diagrams of DCIS and invasive breast cancer in the breast
9	Check understanding about how DCIS differs from invasive breast cancer and clarify any misunderstanding
10	Invite questions specifically about the diagnosis and in general

2.9B *Development of a coding system for the quantitative analysis*

As there are no existing interaction analysis coding systems that focus on communication of diagnosis and prognosis in a DCIS consultation, a coding system was developed by the author from the *Key Communication Elements (DCIS)* for the analysis (see Appendix 4.14). The presence or absence of each of the key elements was recorded. The coding system was discussed with PB (supervisor) who specialises in analysing doctor-patient communication in oncology consultations to ensure codes were appropriate. A manual was developed with definitions of each coding element. Three consultations were coded by two coders (the author and her supervisor PB). Any discrepancies were identified, discussed and resolved, and the manual was revised to provide more precise descriptions to ensure concordance in future coding. This process continued until no further discrepancies were identified (a further three consultations). The author then completed the coding.

2.9C *Quantitative analysis*

Quantitative analysis used descriptive statistics to analyse the following:

- 1) To what extent surgeons communicate in accord with the selected *Key Communication Elements (DCIS)* in the initial diagnostic consultation by examining the number (percentage) of consultations in which surgeons communicated in accord with each of the selected *Key Communication Elements (DCIS)*.
- 2) The key terms and phrases used in consultations to describe DCIS and invasive breast cancer by examining the number (percentage) of consultations in which key terms and phrases were used.
- 3) Whether there are any differences between surgeons in their communication about DCIS by examining:
 - i. the number (percentage) of surgeons who communicated in accord with each of the selected *Key Communication Elements (DCIS)* in at least one consultation
 - ii. the number (percentage) of surgeons who used key terms and phrases to describe the woman's diagnosis in at least one consultation

2.9D *Qualitative analysis*

Qualitative analysis was used to examine the following:

- 1) How surgeons communicate the recommendations in the selected *Key Communication Elements (DCIS)* in the initial diagnostic consultation
- 2) The key terms and phrases surgeons use to describe DCIS and invasive breast cancer

- 3) Whether surgeons communicate about DCIS in the same way to different women and the possible factors contributing to any variation in communication about DCIS to different women

The audio-taped communication was coded into themes (derived from the *Key Communication Elements (DCIS)*) and sub-themes (which emerged from the data) using thematic analysis.²⁵ Themes and sub-themes are exemplified by quotes. In addition, the typical structure of the initial communication in the consultations was identified. Terms and phrases used to describe DCIS and invasive breast cancer were also identified, categorised into themes and exemplified by quotes. Following the coding by the author, the data within each code were discussed with her supervisors to increase the author's understanding of the data and to confirm that the codes were justifiable.

The qualitative data were examined to explore whether surgeons communicate about DCIS in the same way to different women. Differences in surgeon communication with different women were discussed and exemplified by quotes. There was no intention to quantify the variation in communication related to each of the selected *Key Communication Elements (DCIS)* or by *individual* surgeon.

The qualitative data were also examined to explore the possible factors contributing to any variation in communication. Explicit and implicit patient characteristics were explored as possible factors (outlined below). Differences in surgeon communication with different women were discussed and exemplified by quotes. There was no intention to examine whether surgeons systematically communicated differently with different subgroups of women.

- i) *Explicit patient characteristics (characteristics derived from survey data):*
 - a) Woman's ethnicity (English as first language spoken vs English not first language spoken)
 - b) Woman's education (tertiary vs non-tertiary)
 - c) Woman's age (<55 years old vs >65 years old)

- ii) *Implicit patient characteristics (characteristics emerged from the data):*
 - a) Patient characteristics discussed during consultations: 1) the woman's prognostic factors; 2) the woman's medical-related profession
 - b) The woman's communication within the consultation, that is, the woman's informational cues including direct questions and indirect statements immediately preceding information-giving by the surgeon

Due to the small sample of women, the study aimed to raise hypotheses about factors that may have contributed to why the same surgeon communicated differently with different women, to be tested in further research.

3 Results

3.1 Sample

3.1.1 Sample of women diagnosed with DCIS

Participating women (n=30) ranged from 44 to 73 years old, with an average age of 57. Only two women did not speak English as their first language and only one woman was from an Aboriginal or Torres Strait Islander background. Thirty percent of women had a tertiary education. Forty percent of women were currently employed. *Table 4.2* outlines the demographic characteristics of women participating in the study.

Table 4.2: Characteristics of women with DCIS (n=30)

	<i>n (%) of participants</i>
Age at diagnosis	range: 44-73 years mean: 57 years
Educational level	
Non-tertiary	21 (70%)
Tertiary	9 (30%)
Employment	
Not employed (Home duties/ retired/ unable to work)	18 (60%)
Employed (Employed P/T or F/T/ self employed)	12 (40%)
Relationship status	
In a relationship (Married / de facto)	25 (83%)
Not in a relationship (Divorced or separated / widowed / single)	5 (17%)
English as first language	28 (93%)
Aboriginal or Torres Strait Islander	1 (3%)
Missing data = 0	

3.1.2 *Sample of surgeons*

Thirteen surgeons from BreastScreen assessment centres in Melbourne participated in the study, including three surgeons from St Vincent's BreastScreen and ten surgeons from Monash BreastScreen. Approximately seventy percent of surgeons were less than fifty years old. Three surgeons were female and ten surgeons were male. Surgeons consulted with between one and four women diagnosed with DCIS as part of the study, with each surgeon consulting on average with two women diagnosed with DCIS. Three surgeons consulted with one woman, four surgeons consulted with two women, five surgeons consulted with three women, and one surgeon consulted with four women as part of the study. Although surgeons were instructed to audio-tape consultations with no more than three women diagnosed with DCIS, one surgeon audio-taped four consultations and these audio-tapes were all included in the analysis.

3.2 Communication about key aspects of the diagnosis of DCIS during consultations

Table 4.3 summarises the number (percentage) of consultations in which surgeons communicated in accord with each of the selected *Key Communication Elements (DCIS)*. *Section 3.2.2* to *Section 3.2.9* describes how and to what extent surgeons communicated in accord with each of the selected *Key Communication Elements (DCIS)* and the key terms and phrases used to describe DCIS and invasive breast cancer, using the results from the qualitative and quantitative analyses.

3.2.1 Summary of the extent to which surgeons communicated in accord with each of the selected Key Communication Elements (DCIS)

Table 4.3 summarises the number (percentage) of consultations in which surgeons communicated in accord with each of the selected *Key Communication Elements (DCIS)*.

Table 4.3: Number (percentage) of consultations (n=30) in which surgeons communicated in accord with each of the selected Key Communication Elements (DCIS)

10 Key Communication Elements (DCIS)		n (%) of consultations
Information-giving behaviours		
1	Reassure the woman that she <u>does not</u> have breast cancer as we commonly understand it, that is, invasive breast cancer	25 (83%)
2	Tell the woman she has ductal carcinoma in situ or DCIS (or carcinoma in situ or in situ cancer)	24 (80%)
3	Explain how DCIS differs from invasive breast cancer:	
i	Explain that DCIS cannot spread to other parts of the body unlike invasive breast cancer	18 (60%)
ii	Explain that DCIS cannot cause death unlike invasive breast cancer	7 (23%)
iii	Explain the breast tissue pathology, that is, that the abnormal or cancer cells are contained in the milk ducts of the breast in DCIS unlike in invasive breast cancer in which they have spread outside the milk ducts	20 (67%)
4	Explain the natural history of DCIS including the uncertainty:	
i	Explain DCIS either as a <u>precursor</u> to invasive breast cancer OR Explain DCIS as a <u>risk</u> for developing invasive breast cancer	26 (87%)
ii	Explain that not all women with DCIS will develop invasive breast cancer if they are not treated	15 (50%)
iii	Explain the uncertainty about knowing which DCIS women would develop invasive breast cancer	5 (17%)
iv	Explain the uncertainty about the exact proportion of DCIS women who would develop invasive breast cancer	1 (3%)
v	Explain the uncertainty about knowing how long after the DCIS diagnosis invasive breast cancer would develop	5 (17%)
5	Explain the provisional nature of prognostic information:	
i	Explain that more information needed for treatment decision-making will be obtained when the pathologist examines the breast tissue removed during surgery	26 (87%)
ii	Explain that invasive breast cancer may be found during surgery	18 (60%)
iii	Reassure the woman that, at this stage, she does not have invasive breast cancer	18 (60%)

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10 Key Communication Elements (DCIS)		n (%) of consultations
Information-giving behaviours		
6	<i>Explain the aim and importance of treatment:</i>	
i	Explain that treatment for DCIS aims to remove the DCIS to help prevent invasive breast cancer from developing in the breast	20 (67%)
7	<i>Reassure the woman of an excellent prognosis after treatment:</i>	
i	Explain that most women diagnosed and treated for DCIS will not develop invasive breast cancer or DCIS again in that breast OR that in most women treatment for the DCIS results in complete cure	28 (93%)
Communication behaviours: Facilitating understanding		
8	<i>Use diagrams of DCIS and invasive breast cancer in the breast:</i>	21 (70%)
i	printed diagram	11 (37%)
ii	draws diagram	4 (13%)
iii	mammogram	10 (33%)
9	<i>Check the woman's understanding about how DCIS differs from invasive breast cancer</i>	0 (0%)
10	<i>Invite questions:</i>	
i	specifically about the diagnosis	3 (10%)
ii	in general	18 (60%)

3.2.2 ***Key Communication Element (DCIS) 1: Reassure the woman that she does not have invasive breast cancer***

In 83% of consultations the surgeon reassured the woman that she did not have invasive breast cancer, as shown in *Table 4.4*. In 43% of consultations the surgeon reassured the woman that she did not have invasive breast cancer by describing the woman's diagnosis as a "pre-cancer", "pre-cancerous" or "pre-invasive" condition.

"Now it sounds pretty serious, but in fact, what it really is, is a precursor or pre-cancerous lesion."

“Now, what that biopsy indicates is not breast cancer, but a condition called ‘ductal carcinoma in situ’ which is better thought of as a form of pre-cancer.”

In some consultations the surgeon reassured the woman that her diagnosis was “a step back from cancer” or “not yet a cancer”.

“It is probably the step back from cancer.”

“That’s right. Now, what we got out from there is not yet a cancer. But it’s an area that has the potential to become a cancer.”

Surgeons frequently used terms and euphemisms in the consultations to describe invasive breast cancer such as “true cancer”, “real cancer”, and “ordinary breast cancer”.

“This is not the normal breast cancer that people talk about every day in newspapers and in the community. There’s a lot more written about ordinary breast cancer. But that doesn’t pertain to you. So don’t read those big books about breast cancer because you’ll get the wrong idea. Alright and they don’t apply to you.”

Other terms and euphemisms surgeons used to describe invasive breast cancer included “full blown cancer”, “something significantly more nasty”, “cancer that starts to spread”, “more progressive form of breast cancer”, and “a more aggressive cancer”. The use of these terms and euphemisms may be misunderstood by some women as indicating that they do not have metastatic breast cancer rather than that they do not have invasive breast cancer.

“You’ve got a bit of a problem, I would say you haven’t got a major problem, but you’ve got a bit of a problem that needs to be dealt with because if you don’t have something done about it you could get a full blown cancer.”

“But if it was left there it could develop into an invasive cancer, so, um, it needs to be removed to prevent it developing into a more progressive form of breast cancer.”

In some consultations the surgeon described the woman’s diagnosis as a “special type” or “different type” or “different form” of breast cancer or cancer. In two consultations the surgeon described the woman’s diagnosis as a “non-invasive breast cancer” or “non-invasive cancer”.

“It’s a special type of cancer which is a little different to what you imagine when you imagine a kind of a lump is breast cancer.”

“It’s what we call non-invasive breast cancer.”

Table 4.4 outlines the number of consultations in which surgeons communicated in accord with the *Key Communication Element (DCIS) 1* with examples of surgeon communication.

Table 4.4: Number (percentage) of consultations (n=30) in which surgeons communicated in accord with Key Communication Element (DCIS) 1

Key Communication Element (DCIS) 1: Reassure the woman that she <u>does not</u> have breast cancer as we commonly understand it, that is, invasive breast cancer	
n (%) of consultations	Examples
25 (83%)	<ul style="list-style-type: none"> “Now, we’re not dealing breast cancer, but we’re dealing with a condition called Ductal Carcinoma in Situ. DCIS. Now it sounds pretty serious, but in fact, what it really is, is a precursor or pre-cancerous lesion.” “It does look like we are dealing with this pre-cancerous change. Now, um – what does that mean? Well, pre-cancer by itself never hurt anybody. It just sits there, but clearly it has the potential over the years – and I really do mean years ahead – to do something bad, like turn into breast cancer. The important thing I think to emphasise to you at this stage is that the changes are precancerous that there is no evidence that cancer has developed.” “It’s still not invasive, so therefore it’s not real cancer, it’s not the sort of tumour that can spread throughout your body and kill you. But it is another step along.” “So we are talking about early cancer change inside the milk duct. This is not the normal breast cancer that people talk about every day in newspapers and in the community.”

Table 4.5 outlines terms and euphemisms surgeons used during the consultations to communicate to the woman that she did not have invasive breast cancer with examples of surgeon communication.

Table 4.5: Terms and euphemisms used to describe the woman's diagnosis as not invasive breast cancer

Euphemisms and terms used to describe the woman's diagnosis	Examples
not invasive breast cancer or invasive cancer	<ul style="list-style-type: none"> • <i>"It's not, from what we can see, an invasive cancer."</i>
not breast cancer or cancer	<ul style="list-style-type: none"> • <i>"Now, in your case, the needle test has shown something that is abnormal. Whilst it's not breast cancer."</i>
not true cancer	<ul style="list-style-type: none"> • <i>"The first thing to say is the biopsy has shown some change in the breast. It's not a true breast cancer or anything like that."</i>
not real breast cancer	<ul style="list-style-type: none"> • <i>"Oh, although this shows Carcinoma in Situ, when we look at the whole lump there may be some real cancer there."</i>
not full-blown cancer	<ul style="list-style-type: none"> • <i>"It hasn't turned into a full blown cancer"</i>.
not proper breast cancer	<ul style="list-style-type: none"> • <i>"It's not proper breast cancer – so we've caught it before it's turned into something significantly more nasty."</i>
not normal breast cancer	<ul style="list-style-type: none"> • <i>"This is not the normal breast cancer that people talk about. Every day in newspapers and in the community."</i>
not ordinary breast cancer	<ul style="list-style-type: none"> • <i>"There's a lot more written about ordinary breast cancer. But that doesn't pertain to you."</i>
not typical breast cancer	<ul style="list-style-type: none"> • <i>"It's not the typical breast cancer that people talk about."</i>
not conventional breast cancer	<ul style="list-style-type: none"> • <i>"And again that's why this is a bit different to the kind of conventional sort of cancer that people talk about."</i>
not cancer that can spread	<ul style="list-style-type: none"> • <i>"It is different to the type of cancer when you think 'Oh, gee, you know, cancer can pop up in other places at other times.'"</i>
not progressive form of breast cancer	<ul style="list-style-type: none"> • <i>"It needs to be removed to prevent it developing into a more progressive form of breast cancer."</i>
not a more aggressive cancer	<ul style="list-style-type: none"> • <i>"Um, it will eventually develop into a more aggressive cancer."</i>
a pre-cancer or pre-cancerous or pre-invasive condition	<ul style="list-style-type: none"> • <i>"What the biopsy has shown is this is what we call, um, a pre-cancerous lesion."</i>
a non-invasive breast cancer or non-invasive cancer	<ul style="list-style-type: none"> • <i>"It's what we call non-invasive breast cancer."</i>

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Euphemisms and terms used to describe the woman's diagnosis	Examples
a special or different type or form of breast cancer or cancer	<ul style="list-style-type: none"> • <i>"It's a special type of cancer which is a little different to what you imagine when you imagine a kind of a lump is breast cancer."</i> • <i>"The difference between this type of cancer and the kind of other type is that this type of cancer doesn't have the ability to spread to other parts of the body."</i>
a step back from cancer	<ul style="list-style-type: none"> • <i>"It is probably the step back from cancer".</i>
not yet a cancer	<ul style="list-style-type: none"> • <i>"Now, what we got out from there is not yet a cancer. But it's an area that has the potential to become a cancer."</i>

Responses are not mutually exclusive.

In 40% of consultations the surgeon described the woman's diagnosis as an "early breast cancer", "early cancer", "early form of breast cancer" or "early form of cancer". In most of these consultations the woman was also told that she had DCIS or ductal carcinoma in situ and in some of these consultations the surgeon reassured the woman that she did not have invasive breast cancer.

"It's a very early form of breast cancer where it's still confined to the breast, um, so it's not yet what we call an invasive cancer."

In some consultations the surgeon described the woman's diagnosis as early cancer or early breast cancer and did not attempt to reassure the woman that she did not have invasive breast cancer.

"Well, the biopsy of those areas of calcification did show a little area of early cancer developing. Now, of course, that's what we do these screens for. To pick up cancer at an early stage. And this looks to be very much an early stage. There's no evidence that the cancer has spread at all on the biopsy. It looks as if it is just confined to the breast."

In some consultations the surgeon opened the consultation by telling the woman that she did not have ‘cancer’ followed by an explanation of how her diagnosis differed from invasive breast cancer.

“The first thing to tell you is that, ah, this is not a breast cancer”.

In other consultations the surgeon opened the consultation by telling the woman that she had “early breast cancer”, “an early type of cancer”, “early changes of breast cancer” or “a special type of breast cancer”.

“I’m afraid I need to tell you that it did show an early cancer. The one in the front of the breast showed an early cancer at a stage before it has begun to spread beyond the breast.”

In some of these consultations the surgeon subsequently or later in the consultation explained to the woman that she did not have invasive breast cancer and explained how her diagnosis differed from invasive breast cancer.

‘It is an early form of breast cancer. Alright. It’s not the typical breast cancer that people talk about, but it is an early stage of breast cancer change.’

3.2.3 Key DCIS Communication Element 2: Tell the woman she has ductal carcinoma in situ or DCIS

In 80% of consultations the surgeon told the woman that she had ductal carcinoma in situ or DCIS (or carcinoma in situ or in situ cancer), as shown in *Table 4.6*. Therefore, the woman was not told the name of her diagnosis in 20% of consultations.

“So the name of what you have is called Ductal Carcinoma in Situ – that’s a big medical term – you’ll hear people around the place call it DCIS.”

Table 4.6 outlines the number of consultations in which surgeons communicated in accord with the *Key Communication Element (DCIS) 2* with examples of surgeon communication.

Table 4.6: Number (percentage) of consultations (n=30) in which surgeons communicated in accord with Key Communication Element (DCIS) 2

Key Communication Element (DCIS) 2: Tell the woman she has ductal carcinoma in situ (or DCIS or carcinoma in situ or in situ cancer)	
n (%) of consultations	Examples
24 (80%)	<ul style="list-style-type: none"> • <i>“The needle test from this area shows that this is what is called Ductal Carcinoma in Situ. That’s the name, alright and we shorten that name down to DCIS. Alright? So it’s easier to talk about. OK”</i> • <i>“Now I actually need to give you a sort of a biology lesson about what it is because it’s got a long winded name, which we call ductal cancer in situ – or DCIS for short.”</i> • <i>“So the name of what you have is called Ductal Carcinoma in Situ – that’s a big medical term – you’ll hear people around the place call it DCIS.”</i>

Table 4.7 outlines the number of consultations in which key terms such as “ductal carcinoma in situ”, “pre-cancer”, and “early breast cancer” were used to describe the woman’s diagnosis.

Table 4.7: Number (percentage) of consultations (n=30) in which the following key terms were used to describe the woman's diagnosis

Terms used to describe the woman's diagnosis	n (%) of consultations
i DCIS or ductal carcinoma in situ or carcinoma in situ or in situ cancer	24 (80%)
ii pre-cancer or pre-cancerous or pre-invasive condition	13 (43%)
iii DCIS or ductal carcinoma in situ or carcinoma in situ or in situ cancer <u>AND</u> pre-cancer or pre-cancerous or pre-invasive condition	10 (33%)
iv pre-cancer or pre-cancerous or pre-invasive condition <u>only</u>	3 (10%)
v early breast cancer or early cancer or early form of breast cancer	12 (40%)
vi DCIS or ductal carcinoma in situ or carcinoma in situ or in situ cancer <u>AND</u> early breast cancer or early cancer or early form of breast cancer	9 (30%)
vii early breast cancer or early cancer or early form of breast cancer <u>only</u>	3 (10%)
viii non-invasive breast cancer or non-invasive cancer	2 (7%)
ix a special or different type or form of breast cancer or cancer	5 (17%)
x tumour	6 (20%)

Responses are not mutually exclusive.

3.2.4 Key Communication Element (DCIS) 3: Explain how DCIS differs from invasive breast cancer

In 60% of consultations the surgeon explained to the woman that her diagnosis cannot spread to other parts of the body unlike invasive breast cancer, as shown in *Table 4.8*.

“It’s not real cancer, it’s not the sort of tumour that can spread throughout your body.”

Therefore, in 40% of consultations the surgeon did not explain to the woman that her diagnosis cannot spread to other parts of the body unlike invasive breast cancer. In addition, in some consultations the surgeon incorrectly described the woman's diagnosis as cancer or cancer in situ that was “still confined to the breast” and “at a stage before it

has begun to spread beyond the breast” rather than confined to the ducts and at a stage where it cannot spread.

“Well, the biopsy of those areas of calcification did show a little area of early cancer developing. Now, of course, that’s what we do these screens for. To pick up cancer at an early stage. And this looks to be very much an early stage. There’s no evidence that the cancer has spread at all on the biopsy. It looks as if it is just confined to the breast.”

“It showed an early cancer at a stage before it has begun to spread beyond the breast.”

In only 23% of consultations was the woman explicitly told that her diagnosis, unlike invasive breast cancer, cannot cause death.

“Because, if that’s all it is, that’s not a lethal condition. People don’t die from that. People can die from a true cancer”.

In some consultations the surgeon used euphemisms such as “never hurt anybody” and “no problem to you” to describe DCIS and “more dangerous” and “do something bad” to describe invasive breast cancer and to indicate the different consequences from these diseases.

“Well, pre-cancer by itself never hurt anybody. It just sits there, but clearly it has the potential over the years – and I really do mean years ahead – to do something bad, like turn into breast cancer.”

“Now, these cells that are turning to cancer cells could, as time goes by, if they are left alone, turn into invasive cancer cells and be obviously more important and more dangerous if that happens.”

Table 4.8 outlines the number of consultations in which surgeons communicated in accord with the *Key Communication Elements (DCIS) 3i- 3ii* with examples of surgeon communication.

Table 4.8: Number (percentage) of consultations (n=30) in which surgeons communicated in accord with Key Communication Elements (DCIS) 3i-3ii

Key Communication Element (DCIS) 3: Explain how DCIS differs from invasive breast cancer	
n (%) of consultations	Examples
<i>i. Explain that DCIS cannot spread to other parts of the body unlike invasive breast cancer</i>	
18 (60%)	<ul style="list-style-type: none"> “In this Ductal Carcinoma in Situ, the cells have started multiplying and they look very abnormal. They look like cancer cells. Um, an in fact they are cancer cells. But they are still all trapped within the duct. So they can’t get out and spread anywhere else in the body. Whereas with true cancer, invasive cancer, they’ve actually gone through the wall, and so they have the potential to spread elsewhere.” “The difference between this type of cancer and the kind of other type....is that this type of cancer doesn’t have the ability to spread to other parts of the body.” “They are inside the milk duct but they haven’t gone outside. Once they go outside they become invasive cancer. And of course after becoming invasive cancer if you leave it for a few years then we believe it could spread elsewhere in the body. So in terms of first making a diagnosis we caught it right in the middle. Very early. Hasn’t become cancer. Hasn’t got the ability to spread. But it has got the potential. And what that means for you is that we would recommend that you have a treatment.”
<i>ii. Explain that DCIS cannot cause death unlike invasive breast cancer</i>	
7 (23%)	<ul style="list-style-type: none"> “It’s still not invasive, so therefore it’s not real cancer, it’s not the sort of tumour that can spread throughout your body and kill you.” “Because, if that’s all it is, that’s not a lethal condition. People don’t die from that. People can die from a true cancer.”

The surgeon explained the breast tissue pathology of DCIS and invasive breast cancer in 67% of consultations. Table 4.9 outlines the number of consultations in which the *Key Communication Elements (DCIS) 3ii* was communicated with examples of surgeon communication.

Table 4.9: Number (percentage) of consultations (n=30) in which surgeons communicated in accord with Key Communication Element (DCIS) 3iii

Key Communication Element (DCIS) 3: Explain how DCIS differs from invasive breast cancer	
n (%) of consultations	Examples
iii. Explain the breast tissue pathology, that is, that the abnormal cells (or cancer cells) are contained in the milk ducts of the breast in DCIS unlike in invasive breast cancer in which they have spread outside the milk ducts	
20 (67%)	<ul style="list-style-type: none"> “This is a diagram here of what the breast looks like on the inside and these little tubes – these are the milk ducts and you have thousands of these little tubes in the breast because they are very tiny. Like little water pipes really Alright? Except they often carry milk when you are having children of course. Inside these little tiny pipes the lining of the duct is made up of cells Alright? And that’s just a diagram there of what the lining looks like. It’s usually smooth with the cells around there, just like the lining of your mouth. It’s nice and smooth. Alright? But sometimes these cells grow abnormally and can become cancer cells. Now, if they grow into cancer cells they often start just by growing inside the milk duct itself like in little heaps inside the tube and that we call <i>In Situ</i> or ‘inside’ – alright? ‘Ductal’ because it’s the milk duct we are talking about and ‘Carcinoma’ is just a long word for cancer change. So we are talking about early cancer change inside the milk duct. Alright? This is not the normal breast cancer that people talk about every day in newspapers and in the community. What happens there is that these cancer cells as they grow more and more can actually grow through the milk duct wall into the surrounding fat and tissues. That we call ‘invasion’ or invasive breast cancer and that’s the normal sort of breast cancer but in your biopsy we don’t have any invasion noted. It is all inside the milk duct or ‘<i>In situ</i>’ right now they appear to be all confined inside the milk ducts and so it is totally a curable situation.”

In half of the consultations the surgeon described the breast cells in DCIS as “cancer cells” (with or without the use of abnormal cells).

“This is what we call, something called DCIS, or Ductal Cancer In Situ, “In Situ” means the cancer cells are still within the duct.”

In 20% of consultations the surgeon described the breast cells in DCIS as “abnormal cells” or “abnormalities” only.

“And then, instead of they’re nice and normal looking cells, then you start getting odd shaped cells, they’re doing the wrong thing. And this is where you are, but all those cells that are abnormal in you, are confined inside the duct, and that’s good, because it means nothing’s spread, it hasn’t gone to this.”

Other terms and phrases used by the surgeon to describe the breast cells in DCIS include ‘malignant cells’, ‘cells go haywire’ and ‘rust in a pipe’.

“And what that actually means is that there are some cancer cells sitting in the area with the calcium, which is a very small area in your right breast, but they are sitting in the milk ducts like rust in a pipe.”

Table 4.10 outlines the number (percentage) of consultations in which terms such as “cancer cells” or phrases such as “cells go haywire” were used to describe the breast cells in DCIS with examples of surgeon communication.

Table 4.10: Number (percentage) of consultations (n=30) in which the following terms and phrases were used to describe the breast cells in DCIS in the breast tissue

Terms and phrases to describe breast cells in DCIS		n (%) of consultations	Examples
i	cancer cells (with or without abnormal cells)	15 (50%)	<ul style="list-style-type: none"> “The cells have started multiplying and they look very abnormal. They look like cancer cells. Um, and in fact they are cancer cells.” “They really are cancer cells but they’re all trapped within the duct.” “This is what we call, something called DCIS, or Ductal Cancer In Situ, “In Situ” means the cancer cells are still within the duct.” “Yeah, sort of – ah – an early type of breast cancer – um – where the cells, some of the cells, in the ducts of the breast are showing cancerous change.”

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Terms and phrases to describe breast cells in DCIS		n (%) of consultations	Examples
ii	abnormal cells or abnormalities (and no cancer cells)	6 (20%)	<ul style="list-style-type: none"> • <i>“The cells themselves show abnormalities.”</i> • <i>“And then, instead of they’re nice and normal looking cells, then you start getting odd shaped cells, they’re doing the wrong thing. And this is where you are, but all those cells that are abnormal in you, are confined inside the duct, and that’s good, because it means nothing’s spread, it hasn’t gone to this.”</i> • <i>“And they can go from normal breast tissue and then they show some changes and then they become DCIS, which looks somewhat like this, these are cells. Which is abnormal. Inside the milk duct but they haven’t gone outside.”</i>
iii	other	4 (13%)	
a	malignant cells	2 (7%)	<ul style="list-style-type: none"> • <i>“Sometimes they can change their appearance and look like a malignant cell. And they can fill the duct with malignant looking cells.”</i>
b	cells go haywire	1 (3%)	<ul style="list-style-type: none"> • <i>“But then they start to get a bit disordered and the cells themselves actually change, mutate if you like. Go haywire. And, but they’re still trapped within that duct.”</i>
c	rust in a pipe (and cancer cells)	1 (3%)	<ul style="list-style-type: none"> • <i>“And what that actually means is that there are some cancer cells sitting in the area with the calcium, which is a very small area in your right breast, but they are sitting in the milk ducts like rust in a pipe.”</i>

3.2.5 Key Communication Element (DCIS) 4: Explain the natural history of DCIS including the uncertainty

Surgeons explained the natural history of DCIS to the woman in 87% of consultations, as shown in *Table 4.11*. The woman’s diagnosis was described as a precursor to invasive breast cancer, rather than increasing the risk of developing invasive breast cancer, in all consultations.

In some consultations the surgeon used the terms “DCIS” (or ductal carcinoma in situ or in situ cancer) and “invasive breast cancer” (or invasive cancer) to explain the natural history of DCIS.

“Now we think that probably if we left Ductal Carcinoma in Situ, it may go on to invasive cancer.”

In some consultations the surgeon used the terms “pre-cancer” and “breast cancer” or “cancer” to explain the natural history of DCIS.

“Now, if you stop and think about it, pre-cancer will only cause troubles when it turns into cancer.”

In some consultations the surgeon used euphemisms for invasive breast cancer such as “true cancer” and “real cancer” to explain the natural history of DCIS.

“So if everything that you’ve got there is just that, that’s fine, that’s not a risk to you, except it could change and become a true cancer.”

In other consultations, the surgeon used terms and euphemisms for invasive breast cancer such as “cancer that starts to spread”, “more progressive form of breast cancer”, and “a more aggressive cancer” to explain the natural history of DCIS. These terms and euphemisms may indicate to some women that their diagnosis is a precursor to metastatic breast cancer rather than early invasive breast cancer.

“Um, it will eventually develop into a more aggressive cancer, but that may take three months, it may take three years.”

“It needs to be removed to prevent it developing into a more progressive form of breast cancer.”

In one consultation the surgeon used the terms “non-invasive breast cancer” and “invasive breast cancer” to explain the natural history of DCIS.

“So the treatment for this – and why do we treat it? We treat it – if we don’t treat it, there’s a chance that this non-invasive cancer will progress and become an invasive cancer at some stage down the track.”

The natural history of DCIS was not communicated to the woman in 13% of consultations. In these consultations the surgeon frequently described the woman’s diagnosis as early breast cancer that would spread if left untreated.

“It will produce a larger lump and eventually it will spread. And it could then kill you. Now this is very early, so it is very easy to treat.”

Some women with DCIS will develop invasive breast cancer if they are not treated. However, it is not possible to accurately predict which women with DCIS will go on to develop invasive breast cancer.² Furthermore, the evidence estimating the proportion and timeframe of DCIS progression to invasive breast cancer is uncertain as no direct observations are possible due to the current standard of surgical removal of the DCIS.² The best estimates are that 14% to 53% of untreated DCIS may progress to invasive breast cancer over a period of ten years or more.²

In less than half of consultations the surgeon explained that not all women would develop invasive breast cancer if they were not treated. In some consultations the surgeon conveyed the uncertainty about the natural history of DCIS by explaining that “[DCIS] has the potential”, “it could”, and “it may” develop into invasive breast cancer.

‘But if it was left there it could develop into an invasive cancer.’

“Clearly it has the potential over the years – and I really do mean years ahead – to do something bad, like turn into breast cancer.”

In some consultations the surgeon conveyed the uncertainty about the natural history of DCIS by using words such as “many” or “a few” to describe the proportion of women who would develop invasive breast cancer if untreated.

“Um, if we left Ductal Carcinoma in Situ, if we didn’t treat it, we think that many people would go on to get invasive cancer in that area.”

“In a few people who, they have left it in the past, not everyone does go on to get invasive cancer.”

In some consultations the surgeon conveyed the uncertainty about the natural history of DCIS by using proportions and percentages of women who would develop invasive breast cancer if untreated.

“You’ve got these malignant looking cells in a duct that we just know from experience, if we left alone, there would be about a 25% chance of the cells moving and forming a true cancerous lump over the next five years.”

“There’s a chance that this non-invasive cancer will progress and become an invasive cancer at some stage down the track. That varies – I mean, one in five ladies that will happen, the other four, one in five ladies will have the cancers become invasive, four may not have any problems at all.”

Surgeons used different statistics to describe the proportions and percentages of women who would develop invasive breast cancer if untreated.

*“We know that in about **50 to 60%** of people who have what you’ve got, which I’m about to describe, if it’s left alone it will turn into a breast cancer, proper breast cancer.”*

*“You’ve got these malignant looking cells in a duct that we just know from experience, if we left alone, there would be about a **25%** chance of the cells moving and forming a true cancerous lump over the next five years.”*

In only one consultation did the surgeon convey to the woman the uncertainty about the proportion or percentage of women who would develop invasive breast cancer if left untreated.

*“In a few people who, they have left it in the past, not everyone does go on to get invasive cancer. I mean **maybe** 30 or 40% of people go on over the next 10 years to develop invasive cancer.”*

In a few consultations the surgeon told the woman that her diagnosis would develop into invasive breast cancer if left untreated.

“We, we know that if, if nothing is done, or we believe that this will progress no matter, will eventually turn into a full blown cancer if nothing was done.”

In only 17% of consultations did the surgeon explain to the woman the uncertainty about knowing which women would develop invasive breast cancer.

“Unfortunately we don’t know how to predict which people who have this problem will definitely get breast cancer and which will not. We know about 50 to 65 percent of people who have this, if it’s left alone, will develop breast cancer at some point in that area. But we are not smart enough yet to know who they are. We would like one day to have a test where we did your needle test, like you’ve had and we could say to you, well look that’s there and we’ll keep an eye on it with the x rays but we don’t need to do anything. At the moment we can’t tell that.”

Similarly, in only 17% of consultations did the surgeon explain to the woman the uncertainty about knowing how long after the diagnosis invasive breast cancer would develop in the breast.

“Nobody really knows how long they take to become cancer. It may be 6 months, it may be 5 years. It’s very hard to say.”

*“We treat it – if we don’t treat it, there’s a chance that this non-invasive cancer will progress and become an invasive cancer **at some stage down the track.**”*

Table 4.11 outlines the number of consultations in which surgeons communicated in accord with the *Key Communication Elements (DCIS) 4i-4v* with examples of surgeon communication.

Table 4.11: Number (percentage) of consultations (n=30) in which surgeons communicated in accord with Key Communication Elements (DCIS) 4i-4v

Key Communication Element (DCIS) 4: Explain the natural history of DCIS	
n (%) of consultations	Examples
<i>i. Explain DCIS either as a <u>precursor</u> to invasive breast cancer OR Explain DCIS as a <u>risk</u> for developing invasive breast cancer</i>	
26 (87%)	<ul style="list-style-type: none"> “Um, if we left Ductal Carcinoma in Situ, if we didn’t treat it, we think that many people would go on to get invasive cancer in that area.” “Well, pre-cancer by itself never hurt anybody. It just sits there, but clearly it has the potential over the years – and I really do mean years ahead – to do something bad, like turn into breast cancer.” “We treat it – if we don’t treat it, there’s a chance that this non-invasive cancer will progress and become an invasive cancer at some stage down the track.”
<i>ii. Explain that not all women with DCIS will develop invasive breast cancer if they are not treated</i>	
15 (50%)	<ul style="list-style-type: none"> “And so that – these type of cancer cells actually can’t get out of the milk duct and form a lump in the tissue. Some of them, if we leave them, will change enough to be able to kind of break down that, that membrane and get out and make a lump in the tissues. Some of them probably would stay within the milk duct forever. And we don’t actually know how to tell the difference between the two.” “In a few people who, they have left it in the past, not everyone does go on to get invasive cancer. I mean maybe 30 or 40 percent of people go on over the next 10 years to develop invasive cancer. But obviously we’re concerned enough about it that we recommend that that area be removed.”

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Key Communication Element (DCIS) 4: Explain the natural history of DCIS

n (%) of consultations

Examples

iii. Explain the uncertainty about knowing which DCIS women would develop invasive breast cancer

5 (17%)

- “Well the thing is that at the moment we don’t know how to pick which ones will just sit there. And which ones won’t. And although you’re 70 we know that we can prevent this problem happening just by taking this area out.”
- “Unfortunately we don’t know how to predict which people who have this problem will definitely get breast cancer and which will not. We know about 50 to 65% of people who have this, if it’s left alone, will develop breast cancer at some point in that area. But we are not smart enough yet to know who they are. We would like one day to have a test where we did your needle test, like you’ve had and we could say to you, well look that’s there and we’ll keep an eye on it with the x rays but we don’t need to do anything. At the moment we can’t tell that.”

iv. Explain the uncertainty about the exact proportion of DCIS women who would develop invasive breast cancer

1 (3%)

- “In a few people who, they have left it in the past, not everyone does go on to get invasive cancer. I mean **maybe** 30 or 40% of people go on over the next 10 years to develop invasive cancer.”

v. Explain the uncertainty about knowing how long after the DCIS diagnosis invasive breast cancer would develop

5 (17%)

- “Um so that it does have the potential to become cancer a couple of years down the line. Nobody really knows how long they take to become cancer. It may be six months, it may be five years. It’s very hard to say. [Patient: You don’t know] Yeah [Patient: No. It’s an unknown quantity] That’s correct. Absolutely. Yeah.”
- “The time it develops into this sort of thing is probably months to years.”

3.2.6 Key Communication Element (DCIS) 5: Explain the provisional nature of prognostic information

The provisional nature of prognostic information was explained to the woman in 87% of consultations, as shown in *Table 4.12*. The surgeon explained to the woman that more information needed for treatment decision-making would be obtained when the pathologist examines the breast tissue removed during surgery.

“But those decisions can’t be made at this stage – we really only can make those once we’ve got more information about it all.”

In some consultations the surgeon discussed prognostic factors such as the size of the DCIS, the grade of the DCIS, and the surgical margins with the woman. The surgeon more commonly discussed the size of the DCIS and surgical margins than the grade of the DCIS. The importance of clear (adequate) surgical margins was explained in terms of ensuring that “it is all out”.

“Um – and you would get a pathology report back from the pathologist and he’ll say, yes, good you’ve got it all out, all the edges are clear, tell us a bit more information about it, and for some people, surgery is all that is necessary. We decide about that after you’ve had the surgery.”

In some consultations the surgeon discussed the importance of having “got it all out” but did not mention surgical margins.

“And then the tissue is sent off and x-rayed to make sure that the part of we’re worried about is out”.

In a few consultations the surgeon explained to the woman that additional surgery may be needed for unclear (inadequate) surgical margins or if “it was not all out”.

“Have we got it all out? And about 90% of the time we have. Occasionally, and remembering I can’t see or feel this at the time of surgery, we’d have to do another bit of surgery to get a little bit more tissue, to make sure we’ve got it all out. OK?”

In only one consultation did the surgeon explain to the woman that unclear (inadequate) surgical margins increased the risk of DCIS recurrence. The increased risk of invasive breast cancer recurrence from unclear (inadequate) surgical margins was not explained in any of the consultations.

“They also look at the edges very carefully to see that it’s clear, because of course you have to get clear edges. Because if you don’t do that it’s going to grow again in that area fairly – at a, in high risk of doing that.”

In some consultations the surgeon explained that the size of the DCIS was an important feature on the pathology report after surgery. The importance of the size of the DCIS was often explained in terms of how it would affect the treatment options recommended, for example, whether a mastectomy or breast conserving surgery, or additional radiotherapy was recommended.

“However, if the surgeon or pathologist felt that it was going over a reasonable sized area, because sometimes the calcium we see on the mammogram doesn’t represent the whole picture. It’s a fairly good guide, but we have to be a bit careful. You have to go in before you find out really what’s...exactly. So if we were to find that it’s a bit more extensive than we thought, we might say to you ‘look if you had some radiotherapy treatment as well, it would just minimize any chance of anything coming back in the breast’.”

In only two consultations did the surgeon explain to the woman that the size of the DCIS would also affect the risk of DCIS recurrence. It was not explained to the woman in any of the consultations that larger DCIS lesions had a greater risk of invasive breast cancer recurrence than smaller DCIS lesions.

“We know that if an extensive area of the breast has got precancerous change, even though the mammogram looks alright now, and we know the breast tissue looks alright now, there is an increased chance that that other part of the breast tissue may turn precancerous in years to come. What I’m saying here then is that – OK – we can remove that pre-cancer but it may well be worthwhile strongly considering removing all the breast tissue, which is a mastectomy.”

In some consultations the surgeon explained that the grade of the DCIS was an important feature on the pathology report after surgery. The importance of the grade of the DCIS was often explained in terms of how it would affect whether additional radiotherapy was recommended.

“We talk about DCIS in terms of grades – low, intermediate and high grade. Yours is described here as being low grade. If the whole of it proves to be low grade DCIS you may not need to have radio therapy. The future treatment plan will depend on the pathology evaluation of the whole of the little area that comes out. And that can be ... Now if it’s all a tiny little area of low grade DCIS you may well not need radiotherapy. But if it is intermediate grade or higher grade we would normally recommend radiotherapy for the remainder of the breast tissue.”

In a few consultations the surgeon used euphemisms such as “not too active” or “it’s a bit active” to discuss the grade of the DCIS.

“The smaller the area – if the pathologist tells us the area is quite small, and not too active, then probably no radiotherapy. If he says, “oh, you know, it’s a bit active” and the size is a bit bigger, relatively speaking, then we say OK, some radiotherapy afterwards”.

In only one consultation did the surgeon explain to the woman that the grade of the DCIS would affect the risk of DCIS recurrence.

“And then, depending on the final results, how big it is, um, if, and, ah, something called the grade. Which is sort of what it looks like under the microscope, sometimes some radiotherapy is recommended is recommended as well, just to decrease the risk of it coming back again.”

In only one consultation did the surgeon explain to the woman that the grade of the DCIS would affect the risk of invasive breast cancer recurrence.

“There are a couple of different types of DCIS. There’s a high grade, which we believe is more likely to turn into breast cancer, and there is a low grade.”

Table 4.12 outlines the number of consultations in which surgeons communicated in accord with the *Key Communication Element (DCIS) 5i* with examples of surgeon communication.

Table 4.12: Number (percentage) of consultations (n=30) in which surgeons communicated in accord with Key Communication Element (DCIS) 5i

Key Communication Element (DCIS) 5: Explain the provisional nature of prognostic information	
n (%) of consultations	Examples
<i>i. Explain that more information needed for treatment decision-making will be obtained when the pathologist examines the breast tissue removed during surgery</i>	
26 (87%)	<ul style="list-style-type: none"> “When we take the pre-cancerous tissue out, we look at it very carefully under the microscope and there are essentially three things we have to be sure of. One, have we got it all out? And about 90% of the time we have. Occasionally, and remembering I can’t see or feel this at the time of surgery, we’d have to do another bit of surgery to get a little bit more tissue, to make sure we’ve got it all out. OK? That’s number one. Have we got it all out? Most times we have. Number two, we want to know the size. Now, the size of the DCIS is important. We believe if it’s quite small in size – that is less than about a centimetre, which seems to be the case with you, that in many occasions just simply removing it is all we need to do. Third thing we look at is what we call the grade – how, not aggressive, but how it looks because some DCISs have a greater propensity to misbehave than others. Now, we put all that together and if we think that there’s little or no chance of the breast, of the pre-cancer coming back then the surgery is all the treatment you need. Occasionally however, and this applies to women who’ve got what we usually – larger areas of DCIS than you have – we may recommend a course of radiotherapy afterwards.” “Um – and you would get a pathology report back from the pathologist and he’ll say, yes, good you’ve got it all out, all the edges are clear, tell us a bit more information about it, and for some people, surgery is all that is necessary. We decide about that after you’ve had the surgery. The smaller the area – if the pathologist tells us the area is quite small, and not too active, then probably no radiotherapy. If he says, “oh, you know, it’s a bit active” and the size is a bit bigger, relatively speaking, then we say OK, some radiotherapy afterwards.”

In 60% of consultations the surgeon explained to the woman that invasive breast cancer may be found during surgery, as shown in *Table 4.13*. Surgeons used the terms “invasive breast cancer” or “invasive cancer” or euphemisms such as “true cancer” to describe invasive breast cancer.

“Now obviously they’ve only sampled, I mean they’ve taken quite a number of samples but they haven’t taken out the whole thing. So we can’t be 100% sure that there’s not some invasive cancer you know, out just past the next bit.”

“Occasionally we get a surprise and there’s a little bit of true cancer there, but not very often.”

In half of the consultations in which the surgeon explained that invasive breast cancer may be found during surgery, the surgeon also explained that if invasive breast cancer was detected this would affect the treatment options recommended to the woman.

“So in a way, if we – we like to diagnose, if we’ve got to diagnose breast cancer, we like to get it at this stage before it’s started to become invasive. The treatment of it is probably a little bit simpler than if it is already invasive breast cancer.”

All of the women who were told that invasive breast cancer may be found during surgery were reassured that, at this stage, they did not have invasive breast cancer.

“But, um, from what we’ve got so far on the biopsies, all they’ve seen is the Ductal Carcinoma in Situ.”

In most consultations the surgeon also provided reassurance to the woman by describing the possibility of detecting invasive breast cancer during surgery as “[a] small possibility” and “pretty unusual” and occurred “not very often” and “very occasionally”.

“Very occasionally we find that once we’ve removed that area there is a little bit of invasive cancer within what we’ve taken out. Um – that’s pretty unusual, but occasionally we do find that’s the case.”

In two consultations the surgeon used a statistic not found in the literature to explain the likelihood of detecting an invasive breast cancer during surgery.

“The other issues you have of your own, is that it, that area requires to be removed just with a small rim of normal tissue surrounding it, and the whole of that to be looked at. Because again, there will also be about a 20% chance that it’s already done that – changed and there’s a little bit of true cancer mixed up with it.”

Table 4.13 outlines the number of consultations in which surgeons communicated in accord with the *Key Communication Elements (DCIS) 5ii-5iii* with examples of surgeon communication.

Table 4.13: Number (percentage) of consultations (n=30) in which surgeons communicated in accord with Key Communication Elements (DCIS) 5ii-5iii

Key Communication Element (DCIS) 5: Explain the provisional nature of prognostic information	
n (%) of consultations	Examples
ii. Explain that invasive breast cancer may be found during surgery	
18 (60%)	<ul style="list-style-type: none"> “Now obviously they’ve only sampled, I mean they’ve taken quite a number of samples but they haven’t taken out the whole thing. So we can’t be 100% sure that there’s not some invasive cancer you know, out just past the next bit. Um, but from what we’ve got so far it’s only just the DCIS. Now I guess there’s a small possibility that when they look at it under the microscope there might be some invasive cancer within it.”
iii. Reassure the woman that, at this stage, she does not have invasive breast cancer	
18 (60%)	<ul style="list-style-type: none"> “Very occasionally we find that once we’ve removed that area there is a little bit of invasive cancer within what we’ve taken out. Um – that’s pretty unusual, but occasionally we do find that’s the case. But, um, from what we’ve got so far on the biopsies, all they’ve seen is the Ductal Carcinoma in Situ.”

3.2.7 Key Communication Element (DCIS) 6: Explain the aim and importance of treatment

Surgeons explained the aim and importance of treatment, that is, to remove the DCIS to help prevent invasive breast cancer from developing in the breast in two thirds of consultations, as shown in *Table 4.14*. In some consultations the surgeon used the terms “DCIS” (or ductal carcinoma in situ or in situ cancer) and “invasive breast cancer” or “invasive cancer” to explain the aim of treatment.

“Now we think that probably if we left Ductal Carcinoma in Situ, it may go on to invasive cancer. So we would normally recommend to have some treatment to prevent that happening.”

In some consultations the surgeon used the terms “pre-cancer” and “breast cancer” or “cancer” to explain the aim of treatment.

“The important thing I think to emphasise to you at this stage is that the changes are precancerous that there is no evidence that cancer has developed, and that by simply by removing precancerous change you remove the opportunity for that pre-cancer to change.”

In some consultations the surgeon used terms and euphemisms for invasive breast cancer such as “true cancer” and “real cancer” to explain the aim of treatment.

“So if everything that you’ve got there is just that, that’s fine, that’s not a risk to you, except it could change and become a true cancer.”

In other consultations, the surgeon used terms and euphemisms for invasive breast cancer such as “cancer that starts to spread”, “more progressive form of breast cancer”, and “a more aggressive cancer” to explain the aim of treatment. These terms and euphemisms may indicate to some women that the aim of treatment is to remove early invasive breast cancer to help prevent metastatic breast cancer.

“It needs to be removed to prevent it developing into a more progressive form of breast cancer.”

In one consultation the surgeon used the terms “non-invasive breast cancer” and “invasive breast cancer” to explain the aim of treatment.

“So the treatment for this – and why do we treat it? We treat it – if we don’t treat it, there’s a chance that this non-invasive cancer will progress and become an invasive cancer at some stage down the track.”

In some consultations the surgeon also explained to the woman that another important aim of treatment was to ensure that any invasive breast cancer in the DCIS lesion was also removed.

“So it ought to be removed for two reasons. First of all to stop it, remove it so it, stop it changing, and also to make sure that the whole of the area is like this, but every now and again we get a surprise and some areas inside the calcification has already changed.”

In a few consultations the surgeon also explained to the woman that treatment aims to reduce the risk of recurrence.

“Anyone who’s had any type of breast cancer has a kind of higher long term risk of getting another one than if they’ve never had it. But most people who get one cancer don’t ever get another one. Now the risk is quoted at about kind of one percent a year, so that anyone who’s had breast cancer once is followed up a bit more closely and sometimes there are options of saying well can we reduce that risk of a second one. And one of the tablets that you may have heard of is a drug called Tamoxifen.”

However, in one third of consultations the surgeon did not explain the aim and importance of treatment for DCIS. In some consultations the surgeon described the aim of treatment as preventing the “spread” or “progression” of the ‘cancer’ as in early invasive breast cancer.

“It will produce a larger lump and eventually it will spread. And it could then kill you. Now this is very early, so it is very easy to treat. But what you need now is to have some surgery.”

In some consultations the surgeon used euphemisms such as “[to] minimise the chance of any more problems” and “[so] you won’t have any more problems with it” to describe the aim of treatment.

“So, provided that we treat it properly here, Uh huh then hopefully you won’t have any more problems with it.”

Table 4.14 outlines the number of consultations in which surgeons communicated in accord with the *Key DCIS Communication Element 6* with examples of surgeon communication.

Table 4.14: Number (percentage) of consultations (n=30) in which surgeons communicated in accord with the Key Communication Element (DCIS) 6

Key Communication Element (DCIS) 6: Explain the aim and importance of treatment	
n (%) of consultations	Examples
20 (67%)	<ul style="list-style-type: none"> “Now we think that probably if we left Ductal Carcinoma in Situ, it may go on to invasive cancer. So we would normally recommend to have some treatment to prevent that happening.” “Now, if you stop and think about it, pre-cancer will only cause troubles when it turns into cancer. The treatment is pretty straight forward and it’s simply to remove the area of pre-cancer.” “And it ought to be removed for two reasons. First of all to stop it, remove it so it, stop it changing, and also to make sure that the whole of the area is like this, but every now and again we get a surprise and some areas inside the calcification have already changed.”

3.2.8 Key Communication Element (DCIS) 7: Reassure the woman of an excellent prognosis after treatment

In 93% of consultations the surgeon reassured the woman of an excellent prognosis after treatment, as shown in *Table 4.15*. In many consultations the surgeon explained to the woman that treatment for her diagnosis was potentially “curable”.

“Probably the bottom line in all this is, while you’ve got to have the treatment, and deal with it, it is a totally curable state of affairs. And that’s the good news part, and it’s good that you’ve found it now.”

In some consultations the surgeon explained to the woman that treatment for her diagnosis resulted in a low risk of recurrence of DCIS or of developing invasive breast cancer.

“It’s something that can be easily dealt with and we know that the – um – in terms of following up patients who have a proper treatment 99% have been cured with the correct treatment. So, so 99% will have no further trouble [Woman: No reoccurrence of that, yes] Exactly, or [Woman: Of that particular spot] or chance of it becoming cancer, that’s right, yeah, that particular spot.”

In many consultations the surgeon also provided hope and reassurance to the woman by explaining that being diagnosed with DCIS was “good news” as well as “bad” because DCIS had been detected before it had developed into invasive breast cancer.

“I say to someone like yourself, the news is both good and bad. It’s good that something that can be done about it. We picked it up at this stage before it’s likely to be mischievous. It’s bad – it’s just you’re going to have to have a bit of surgery. It’s got to have it done and a little bit of radiotherapy. You are a bit more at risk. And so most of us would recommend you have an annual mammogram perhaps from here on in. Well, as I said, I’ve given you news that’s both good and bad. And I do stress that it’s fine. It’s important that you don’t panic.”

In some consultations the surgeon also provided reassurance to the woman by explaining that BreastScreen aims to detect conditions like DCIS.

“That’s why if we have to find something at BreastScreen, we are quite happy actually to find this, because we know that we can fix it and that it hasn’t spread anywhere.”

“The prospects of cure are very, very good indeed, and of course that’s what BreastScreen is all about.”

Table 4.15 outlines the number of consultations in which surgeons communicated in accord with the *Key Communication Element (DCIS) 7* with examples of surgeon communication.

Table 4.15: Number (percentage) of consultations (n=30) in which surgeons communicated in accord with the Key Communication Element (DCIS) 7

Key Communication Element (DCIS) 7: Reassure the woman of an excellent prognosis after treatment	
n (%) of consultations	Examples
28 (93%)	<ul style="list-style-type: none"> • <i>“Um – in this situation it hasn’t got the ability to spread – so if we can remove it we regard it as cured. And then we’re just dealing with saying things like, well, O.K. we’ve had this problem, what’s the risk of having another problem in the future. And can we reduce that risk. So what we would expect is for you to have some treatment and for everything to be fine.”</i> • <i>“I say to someone like yourself, the news is both good and bad. It’s good that something that can be done about it. We picked it up at this stage before it’s likely to be mischievous. It’s bad – it’s just you’re going to have to have a bit of surgery. It’s got to have it done and a little bit of radiotherapy. You are a bit more at risk. And so most of us would recommend you have an annual mammogram perhaps from here on in. Well, as I said, I’ve given you news that’s both good and bad. And I do stress that it’s fine. It’s important that you don’t panic.”</i> • <i>“And that’s the name of the game because the important thing about this problem, about this pre-cancerous change is that now we’ve found it, this is a curable situation. Whereas if we leave things alone and wait till we get a proper breast cancer. That’s why if we have to find something at BreastScreen, we are quite happy actually to find this, because we know that we can fix it and that it hasn’t spread anywhere.”</i>

3.2.9 Facilitating understanding of the information: Key Communication Elements (DCIS) 8-10

In 70% of consultations the surgeon used diagrams such as printed or drawn diagrams or the woman’s mammogram to explain the breast tissue pathology and how DCIS differs from invasive breast cancer, as shown in *Table 4.16*. Surgeons more commonly used printed diagrams or the woman’s mammogram than drew diagrams for the woman. The use of diagrams was inferred from the surgeon’s communication as recorded on the audio-tape (*see example in Table 4.16*).

However, the surgeon did not check the woman’s understanding about her diagnosis in any consultation. Surgeons did not ask the woman to explain her understanding of how DCIS differs from invasive breast cancer. In a few consultations the surgeon asked the woman *whether* she understood how DCIS differs from invasive breast cancer. In one consultation the woman said she understood the information.

“But we know that there’s about at least a 25% chance of those cells moving out of the duct into the breast and forming a true cancerous lump. [Woman: Right] And that could happen in the next, sometimes in the next 10 years. So if everything that you’ve got there is just that, that’s fine, that’s not a risk to you, except it could change and become a true cancer. Does that make sense? [Woman: Yes I can understand that, yes.] Yeah, so it would appear from the biopsy tests that what you’ve got is just this area of DCIS.”

In two consultations the woman seemed uncertain about the information provided but the surgeon continued without further explanation.

“Occasionally they find tiny spots where cells might have got out of the milk duct. Often that doesn’t mean anything different to what we’ve already got and it’s unlikely but sort of possible that they might find something else in the tissue that might change the pathology a bit. But I wouldn’t expect it because they’re tiny, microscopic. Does that make sense? [Woman: Mmm. So far.] Sort of? Um – what happens at this stage is that BreastScreen finds out about stuff for you and tells you what’s going on but it doesn’t actually treat anything.”

In a few consultations the surgeon regularly asked the woman ‘alright?’ after providing information and then continued without any verbal response from the woman.

“It’s really only once it’s through the wall of the duct that it has the potential to spread into the rest of the breast. [Woman: mmm mmm] Alright? So, um, from what we’ve seen at this stage it’s all this Ductal Carcinoma in Situ.”

In only 10% of consultations did the surgeon invite questions from the woman specifically about the diagnosis such as how DCIS differs from invasive breast cancer or the natural history of DCIS.

“Now is there anything else you want to ask me about the condition itself or what I’ve told you?”

In a greater percentage (60%) of consultations the surgeon invited general questions from the woman after discussing treatment options towards the end of the consultation.

“Anything that you want to ask me at this stage, any questions, worries otherwise?”

In one consultation the surgeon suggested to the woman to write down questions for subsequent consultations.

“Write down your questions, because you will think of them now.”

Table 4.16 outlines the number of consultations in which surgeons communicated in accord with the *Key Communication Elements (DCIS) 8-10* with examples of surgeon communication.

Table 4.16: Number (percentage) of consultations (n=30) in which surgeons communicated in accord with the Key Communication Elements (DCIS) 8-10

Key Communication Elements (DCIS) 8-10		n (%) of consultations	Examples
Communication behaviours: Facilitating understanding			
8	use diagrams of DCIS and invasive breast cancer in the breast	21 (70%)	<i>“So what that is, if you have a look at this picture of the breast you can see all the, um, ducts branching away from the nipple and they divide and that’s what makes the milk. If you look at one of those ducts in cross section normally um, it’s lined by one layer of pretty regular looking cells. Ah, they all look very much the same. In this ductal carcinoma in situ, or DCIS for short, ah, the cells within the ducts have started multiplying, so they look very abnormal. They really are cancer cells but they’re all trapped within the duct. And it’s when it gets through the wall of the duct that we call it invasive cancer or true cancer of the breast.”</i>
i	printed diagram	11 (37%)	
ii	draws diagram	4 (13%)	
iii	mammogram	10 (33%)	

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Key Communication Elements (DCIS) 8-10	n (%) of consultations	Examples
Communication behaviours: Facilitating understanding		
9	<i>check the woman's understanding (about how DCIS differs from invasive breast cancer)</i>	0 (0%)
10	<i>invite questions:</i>	
i	specifically about the diagnosis	3 (10%)
		<ul style="list-style-type: none"> • “And this is where you are, but all those cells that are abnormal in you, are confined inside the duct, and that's good, because it means nothing's spread, it hasn't gone to this. Nothing has spread outside. So, I'll stop for a minute. Do you have any questions – I know it's a bit hard, it's a quick tour of breast problems in 10 seconds or less. Does that sort of make a bit of sense?” • “Now is there anything else you want to ask me about the condition itself or what I've told you?”
ii	in general	18 (60%)
		<ul style="list-style-type: none"> • “Anything that you want to ask me at this stage, any questions, worries otherwise?” • “So is there anything else you want to know today from me?”

Responses are not mutually exclusive.

3.3 Are there differences between surgeons in their communication about DCIS?

Table 4.17 outlines the number (percentage) of surgeons who communicated in accord with each of the selected *Key Communication Elements (DCIS)* in at least one consultation. It shows the variation between surgeons in whether they communicated in accord with each of the selected *Key Communication Elements (DCIS)* or not in any consultation. Section 3.3.1 describes key aspects of the DCIS diagnosis that were communicated by all or most surgeons in at least one consultation; and Section 3.3.2 describes key aspects of the DCIS diagnosis that were not communicated by all or most surgeons in any consultation. Section 3.3.3 describes surgeons' use of key terms to describe the woman's diagnosis including the number (percentage) of surgeons who used key terms to describe the woman's diagnosis in at least one consultation.

Table 4.17: Number (percentage) of surgeons (n=13) who communicated in accord with each of the selected Key Communication Elements (DCIS) in at least one consultation

10 Key Communication Elements (DCIS)		n (%) of surgeons (in at least one consultation) (n=13)
<i>Information-giving behaviours</i>		
1	Reassure the woman that she <u>does not</u> have breast cancer as we commonly understand it, that is, invasive breast cancer	10 (77%)
2	Tell the woman she has ductal carcinoma in situ or DCIS (includes also carcinoma in situ or in situ cancer)	13 (100%)
3	Explain how DCIS differs from invasive breast cancer:	
i	Explain that DCIS cannot spread to other parts of the body unlike invasive breast cancer	11 (85%)
ii	Explain that DCIS cannot cause death unlike invasive breast cancer	4 (31%)
iii	Explain the tissue pathology, that is, that the abnormal or cancer cells are contained in the milk ducts of the breast in DCIS unlike in invasive breast cancer in which they have spread outside the milk ducts	11 (85%)
4	Explain the natural history of DCIS including the uncertainty:	
i	Explain DCIS either as a <u>precursor</u> to invasive breast cancer OR Explain DCIS as a <u>risk</u> for developing invasive breast cancer	13 (100%)
ii	Explain that not all women with DCIS will develop invasive breast cancer if they are not treated, that is, some women with DCIS will never develop breast cancer if they are not treated	9 (69%)
iii	Explain the uncertainty about knowing which DCIS women would develop invasive breast cancer	4 (31%)
iv	Explain the uncertainty about the exact proportion of DCIS women who would develop invasive breast cancer	1 (8%)
v	Explain the uncertainty about knowing how long after the DCIS diagnosis invasive breast cancer would develop	4 (31%)

continued next page

10 Key Communication Elements (DCIS)		n (%) of surgeons <i>(in at least one consultation)</i> (n=13)
5	<i>Explain the provisional nature of prognostic information:</i>	
i	Explain that more information needed for treatment decision-making will be obtained when the pathologist examines the breast tissue removed during surgery	13 (100%)
ii	Explain that invasive breast cancer may be found during surgery	10 (77%)
iii	Reassure the woman that, at this stage, she does not have invasive breast cancer	10 (77%)
6	<i>Explain the aim and importance of treatment:</i>	
i	Explain that treatment for DCIS aims to remove the DCIS to help prevent invasive breast cancer from developing in the breast	13 (100%)
7	<i>Reassure the woman of an excellent prognosis after treatment:</i>	
i	Explain that most women diagnosed and treated for DCIS will not develop invasive breast cancer or DCIS again in that breast OR that in most women treatment for the DCIS results in complete cure	13 (100%)
<i>Communication behaviours: Facilitating understanding</i>		
8	<i>Use diagrams of DCIS and invasive breast cancer in the breast:</i>	10 (77%)
i	uses diagram	5 (38%)
ii	draws diagram	4 (31%)
iii	uses mammogram	5 (38%)
9	<i>Check the woman's understanding about how DCIS differs from invasive breast cancer</i>	0 (0%)
10	<i>Invite questions:</i>	
i	specifically about the diagnosis	3 (23%)
ii	in general	10 (77%)
Responses are not mutually exclusive		

3.3.1 Summary of the key aspects of the DCIS diagnosis that were communicated by all or most surgeons in at least one consultation

All surgeons explained the following in at least one consultation:

- the name of the woman's diagnosis (*Key Communication Element (DCIS) 2*)
- the natural history of DCIS, that is, that her diagnosis is a precursor to invasive breast cancer (*Key Communication Element (DCIS) 4i*)
- that more information needed for treatment decision-making would be obtained when the pathologist examines the breast tissue removed during surgery (*Key Communication Element (DCIS) 5i*)
- the aim and importance of treatment (*Key Communication Element (DCIS) 6*)
- the excellent prognosis after treatment (*Key Communication Element (DCIS) 7*)

Most surgeons explained the following in at least one consultation:

- that the woman did not have breast cancer as we commonly understand it (*Key Communication Element (DCIS) 1*)
- that DCIS cannot spread to other parts of the body unlike invasive breast cancer (*Key Communication Element (DCIS) 3i*)
- the breast tissue pathology (*Key Communication Element (DCIS) 3iii*)
- that invasive breast cancer may be found during surgery (*Key Communication Element (DCIS) 5ii*)
- that, at this stage, the woman did not have invasive breast cancer (*Key Communication Element (DCIS) 5iii*)

Most surgeons used diagrams, such as printed or drawn diagrams or the woman's mammogram in at least one consultation (*Key Communication Element (DCIS) 8*).

3.3.2 Summary of the key aspects of the DCIS diagnosis that were not communicated by all or most surgeons in any consultation

Most surgeons did *not* explain to the woman in any consultation the uncertainty about the exact proportion of women who would develop invasive breast cancer (*Key Communication Element (DCIS) 4iv*).

Most surgeons did not invite questions specifically about the diagnosis in any consultation (*Key Communication Element (DCIS) 10i*); and none of the surgeons checked the woman's understanding about the diagnosis in any consultation (*Key Communication Element (DCIS) 9*).

Approximately two thirds of surgeons did *not* explain to the woman in any consultation the following:

- that the woman's diagnosis cannot cause death unlike invasive breast cancer (*Key Communication Element (DCIS) 3ii*)
- the uncertainty about knowing which women would develop invasive breast cancer (*Key Communication Element (DCIS) 4iii*)
- the uncertainty about knowing how long after the diagnosis invasive breast cancer would develop in the breast (*Key Communication Element (DCIS) 4v*)

Approximately one third of surgeons did *not* explain to the woman in any consultation the uncertainty about the natural history, that is, that not all women would develop invasive breast cancer if they were not treated (*Key Communication Element (DCIS) 4i*).

3.3.3 Surgeons' use of key terms to describe the woman's diagnosis

Table 4.18 outlines the number (percentage) of surgeons who used terms such as “ductal carcinoma in situ”, “pre-cancer”, and “early breast cancer” to describe the woman's diagnosis in at least one consultation.

As discussed above, all surgeons explained to the woman the name of her diagnosis, that is, “DCIS” or “ductal carcinoma in situ” or “carcinoma in situ” or “in situ cancer” in at least one consultation. Approximately half of the surgeons used the terms “pre-cancer” or “pre-cancerous condition” or “pre-invasive condition” in at least one consultation; 38% of surgeons used the terms “early breast cancer” or “early cancer” or “early form of breast cancer” in at least one consultation; 31% of surgeons used the terms a “special type” or “different type” or “form” of breast cancer or cancer in at least one consultation; and 15% of surgeons used the terms “non-invasive breast cancer” or “non-invasive cancer” in at least one consultation.

Table 4.18: Number (percentage) of surgeons (n=13) who used the following terms to describe the woman’s diagnosis

Terms used to describe the woman’s diagnosis		n (%) of surgeons <i>(in at least one consultation)</i> (n=13)	n (%) of consultations (n=30)
i	DCIS or ductal carcinoma in situ or carcinoma in situ or in situ cancer	13 (100%)	24 (80%)
ii	pre-cancer or pre-cancerous or pre-invasive condition	7 (54%)	13 (43%)
iii	early breast cancer or early cancer or early form of breast cancer	5 (38%)	12 (40%)
iv	non-invasive breast cancer or non-invasive cancer	2 (15%)	2 (7%)
v	a special or different type or form of breast cancer or cancer	4 (31%)	5 (17%)

Responses are not mutually exclusive

3.4 Do surgeons communicate about DCIS in the same way to different women?

The qualitative data were examined to explore whether surgeons communicate about DCIS in the same way to different women. There was no intention to quantify the variation in communication related to each of the selected *Key Communication Elements (DCIS)* or by *individual surgeon*.

The study found that there was variation in communication in six important areas of the diagnosis of DCIS. First, some surgeons told the woman the name of her diagnosis in some consultations and not others. For example:

Surgeon X/ Woman 1: “We call this carcinoma in situ, which means, it’s a funny word, but it means it’s the earliest stage of change, we believe.”

Surgeon X/ Woman 2: “It’s abnormal, it shows some changes which – um – we would call a pre-cancerous changes in the breast. In other words, it hasn’t turned into a full blown cancer, but the cells themselves show abnormalities.”

Second, some surgeons told the woman how DCIS differs from invasive breast cancer, and explained the breast tissue pathology, in some consultations and not others. Third, some surgeons told the woman the uncertainty about the natural history of DCIS in some consultations and not others. For example:

Surgeon X/ Woman 1: “And so that – these type of cancer cells actually can’t get out of the milk duct and form a lump in the tissue. Some of them, if we leave them, will change enough to be able to kind of break down that, that membrane and get out and make a lump in the tissues. Some of them probably would stay within the milk duct forever. And we don’t actually know how to tell the difference between the two.”

Surgeon X/ Woman 2: “So we know that these cells have to change quite a bit before they can actually break it down and get out and make a lump in the tissue which is what we call a normal cancer. I think one of the things to remember about this is that this is a sort of if you like a special type of cancer because it is at this early stage when it hasn’t started invading the rest of the tissue.”

Fourth, most surgeons explained the provisional nature of information to all women in the study. However, there were differences in how many prognostic factors were discussed with different women. For example:

Surgeon X/ Woman 1: “Now, some patients need to have some radiotherapy to the breast after the surgery. Not always, and the pathology test on yours suggests that you may not need radiotherapy. But a final decision would be made after your surgery.”

Surgeon X/ Woman 2: “Depending on the size, but again, even if you’ve got a little bit of that true cancer within that tiny little area there, whatever you’ve got is very small and, and the outcome, the outlook relates to the size. Now I saw a, you know, if you’ve a tiny little area that size, that’s terrific...(later in consultation) We talk about DCIS in terms of grades – low, intermediate and high grade. Yours is described here as being low grade. If the whole of it proves to be low grade DCIS you may not need to have radio therapy. The future treatment plan will depend on the pathology evaluation of the whole of the little area that comes out. And that can be ... Now if it’s all a tiny little area of low grade DCIS you may well not need radiotherapy. But if it is intermediate grade or higher grade we would normally recommend radiotherapy for the remainder of the breast tissue.”

Fifth, some surgeons told the woman about the possibility of finding an invasive breast cancer in some consultations and not others. For example:

Surgeon X/ Woman 1: “The pathologist will then look at that and say ‘right, it’s all gone’ and all that sort of stuff and check that there’s nothing left at the edges and make sure that there is no proper breast cancer inside it.”

Surgeon X/ Woman 2: “But for most people, exactly such as yourself, it’s perfectly safe just to take out that area. That area and make sure there’s nice clear tissue around it. Depending on what the whole pathology is, we sometimes might say to ladies after that, look, it would be good for you to have some radiotherapy treatment to your breast.”

Sixth, some surgeons explained the aim and importance of treatment in some consultations and not others. For example:

Surgeon X/ Woman 1: “Now, these cells that are turning to cancer cells could, as time goes by, if they are left alone, turn into invasive cancer cells and be obviously more important and more dangerous if that happens. But right now they appear to be all confined inside the milk ducts and so it is totally a curable situation. In order to cure the problem you need to remove the problem.”

Surgeon X/ Woman 2: “As long as it is confined within the milk ducts, simply removing the area will cure that particular problem.”

3.4.1 Possible factors contributing to variation in surgeon communication with different women

Due to the small sample of women, the study aimed to raise hypotheses about factors that may have contributed to why surgeons communicated differently with different women, to be tested in further research. There was no intention to examine whether surgeons systematically communicated differently with different subgroups of women.

Possible factors contributing to the variation in communication are examined and include explicit and implicit patient characteristics (*see Methods Section 2.9 Data analysis Page 277*). Differences in surgeon communication with different women are discussed and exemplified by quotes.

3.4.1.i. Explicit patient characteristics

a) Woman's ethnicity

The woman's ethnicity may be one of the factors that influenced whether the surgeon described the diagnosis as 'not cancer' or an 'early cancer' and whether the woman was told that she had 'ductal carcinoma in situ' or 'DCIS'. The following is an example of how the same surgeon communicated differently with a woman who did not speak English as her first language compared to a woman who spoke English as her first language. The surgeon reassured the woman who spoke English as her first language that her diagnosis was "not invasive" and "not real cancer" and told the woman who did not speak English as her first language that her diagnosis was "breast cancer" and "very, very early stage". The surgeon also used the terms "ductal carcinoma in situ" and "DCIS" with the woman who spoke English as her first language and used the term "carcinoma in situ" with the woman who did not speak English as her first language.

Surgeon X/ Woman 1 (spoke English as her first language): "You now have a small area of what we call low grade ductal carcinoma in situ. Um – and low grade ductal carcinoma in situ is the next step – if you think of it a step-wise process – towards breast cancer. It's still not invasive, so therefore it's not real cancer, it's not the sort of tumour that can spread throughout your body and kill you. But it is another step along. (later) So, you have got the next stage along. D – C – I – S."

Surgeon X/ Woman 2 (did not speak English as her first language):
“The results of the needle have shown changes that are well on the way to being breast cancer. So the results are not good. It shows an area of your breast that has changed and for which you will need some surgery. This is your result which shows what they call Carcinoma in Situ. Breast cancer – do you understand my English and do you understand what I’m saying? Do you need an interpreter at all? [Woman’s husband: She understand but she got a shock, shock.] I understand, er, and I’m, I wish I had better news for you, but this is certainly the results and, although it’s not good news, it should be easy to treat and I suspect that we will be able to cure you without any difficulty. [Woman’s husband: Is the early stage or...] Very, very early stage. Very small and very early.”

In the example above, the woman who did not speak English as her first language had a lower level of education than the woman who spoke English as her first language which may also have influenced the surgeon’s communication (as discussed in the explicit patient characteristics below).

The woman’s ethnicity may also be one of the factors that influenced the prognostic information provided by the surgeon. The following is an example of how the same surgeon communicated differently with a woman who did not speak English as her first language compared to woman who spoke English as her first language. The surgeon discussed more prognostic factors including the grade of the DCIS and their significance with the woman who spoke English as her first language compared to the woman who did not speak English as her first language.

Surgeon X/ Woman 1 (spoke English as her first language): “There are a couple of different types of DCIS. There’s a high grade, which we believe is more likely to turn into breast cancer, and there is a low grade. Overall the DCIS is low grade and not associated with necrosis. In other words the cells haven’t significantly died - it’s so small they haven’t actually measured it. A very small amount of DCIS is in your specimen. And it’s important that that’s all gone. If it was at the margin right there. Then we wouldn’t know what was next to it. And often we have to go back and take some more.”

Surgeon X/ Woman 2 (did not speak English as her first language): “When they remove the whole tissue, it gets looked at under a microscope again, and this time they look at all of the tissue. And a couple of things might happen. The first is that we will get the lump out and they look at it under a microscope, and they may see some cells near the edge of where the knife went. Now if that happens we may have to say to you ‘I’m sorry, we need to do another operation to take a little bit more breast tissue away’.”

In the example above, the woman who did not speak English as her first language had a lower level of education than the woman who spoke English as her first language. In addition, the communication in the consultation also revealed that the woman who did not speak English as her first language had low-grade DCIS. There was no indication from the communication that the woman who spoke English as her first language had low-grade DCIS. These factors may also have influenced the surgeon’s communication (as discussed in the explicit and implicit patient characteristics below).

The woman’s ethnicity may also be one of the factors that influenced whether the surgeon explained the uncertainty about DCIS progression to invasive breast cancer and whether the surgeon explained to the woman the aim and importance of treatment, that is, to remove the DCIS to help prevent invasive breast cancer from developing in the breast. The following is an example of how the same surgeon communicated differently with a woman who did not speak English as her first language compared to a woman

who spoke English as her first language. The surgeon told the woman who spoke English as her first language that removing the DCIS lesion decreased the “risk of developing a breast cancer” and told the woman who did not speak English as her first language that her disease “would produce a larger lump and eventually it will spread” and therefore it needed to be “removed”.

Surgeon X/ Woman 1 (spoke English as her first language): “So within the middle of an area of atypical changes you had an area of carcinoma in situ. Having removed that we should have removed any risk to you of at least that area developing a breast cancer.”

Surgeon X/ Woman 2 (did not speak English as her first language): “It will produce a larger lump and eventually it will spread. And it could then kill you. Now this is very early, so it is very easy to treat. But what you need now is to have some surgery. You need to have this piece of breast tissue removed with an operation.”

In the example above, the woman who did not speak English as her first language had a lower level of education than the woman who spoke English as her first language which may also have influenced the surgeon’s communication (as discussed in the explicit patient characteristics below).

The woman’s ethnicity did not appear to influence whether the surgeon communicated the *Key Communication Element (DCIS)* that involved explaining to the woman that invasive breast cancer may be detected during surgery.

b) Woman’s education

The woman’s education level may be one of the factors that influenced whether the surgeon told the woman the name of her diagnosis. The following is an example of how the same surgeon communicated differently with two women who had tertiary education compared to a woman who did not have a tertiary education. The surgeon told two women who had tertiary education that they had “carcinoma in situ” or “cancer in

situ” but did not tell the name of the diagnosis to the woman who did not have a tertiary education. There were no other differences in the characteristics of the women in this example in terms of age and ethnicity.

Surgeon X/ Woman 1 (tertiary education): “It’s what we call Cancer In Situ.”

Surgeon X/ Woman 2 (tertiary education): “Well the name for it is called [Woman: a ductal cancer] a Ductal cancer [Woman: yes, yes] And it’s called In Situ.”

Surgeon X/ Woman 3 (non-tertiary education): “Well, the biopsy of those areas of calcification did show a little area of early cancer developing. But it’s just a very early cancer, there’s no evidence that it has spread anywhere beyond the breast.”

The woman’s education level may also be one of the factors that influenced whether the surgeon explained the uncertainty about the natural history, that is, that not all women would develop invasive breast cancer if they were not treated. The following is an example of how the same surgeon communicated differently with a woman who had tertiary education compared to two women who did not have a tertiary education. The surgeon explained to the woman who had tertiary education that her disease has “the potential” to develop into breast cancer but did not explicitly explain this to the two women who did not have tertiary education. There were no other differences in the characteristics of the women in this example in terms of age and ethnicity.

Surgeon X/ Woman 1 (tertiary education): “Well, pre-cancer by itself never hurt anybody. It just sits there, but clearly it has the potential over the years – and I really do mean years ahead – to do something bad, like turn into breast cancer.”

Surgeon X/ Woman 2 (non-tertiary education): “Now, if you stop and think about it, pre-cancer will only cause troubles when it turns into cancer.”

Surgeon X/ Woman 3 (non-tertiary education): “And clearly, if you’ve got something that’s pre-cancerous, and you take it away it can’t do anything bad to you. And that’s basically what you need to know.”

The woman’s education level did not appear to influence whether the surgeon communicated other *Key Communication Elements (DCIS)* including that her diagnosis cannot spread to other parts of the body unlike invasive breast cancer; that invasive breast cancer may be detected during surgery; and the aim and importance of treatment.

c) Woman’s age

The woman’s age (<55 years old vs >65 years old) did not appear to influence whether the surgeon communicated the examined *Key Communication Elements (DCIS)* including the name of her diagnosis; that her diagnosis cannot spread to other parts of the body unlike invasive breast cancer; the uncertainty about the natural history of DCIS; that invasive breast cancer may be detected during surgery; and the aim and importance of treatment.

3.4.1.ii. *Implicit patient characteristics*

a) Patient characteristics discussed during consultations

1) Woman’s prognostic factors

The woman’s prognostic factors such as the grade of the DCIS lesion may be one of the factors that influenced the information provided by the surgeon. The following is an example of how the same surgeon was more reassuring about the prognosis and treatment to the woman with small low grade DCIS (as revealed in the communication)

compared to the woman who did not have small low grade DCIS (as suggested by the discussion about radiotherapy). The surgeon also discussed the benefits of the BreastScreen program with the woman with small low grade DCIS but did not discuss the benefits of the BreastScreen program with the woman who did not have small low grade DCIS.

Surgeon X/ Woman 1 (small low grade DCIS): “We talk about DCIS in terms of grades – low, intermediate and high grade. Yours is described here as being low grade. If the whole of it proves to be low grade DCIS you may not need to have radiotherapy. [later in consultation] If you’ve a tiny little area that size, that’s terrific. [later in consultation] Well I think, I mean, this is a reflection of, this is what the program is all about. Is picking up these things even at this so-called pre-malignant and pre-lethal stage, and also when whatever it is, is very tiny. And this is exactly what the program is set to do, because if we pick them up now the results of treatment is significantly better, and certainly you need lesser treatment, is the other thing of course. You don’t need as much treatment at this stage to deal with all this, compared to had you not been prudent and had your X-ray and then a couple of years down the track turned up with a two or three centimetre lump that could have been there much longer and sort of you know, your outcomes would be potentially less good.”

Surgeon X/ Woman 2 (not small low grade DCIS): “Ah yes, but I think – we grade the DCIS in different grades. Oh, and yours is of a grade that we would routinely give chemo, ah give radiotherapy [Woman: Radio] But not chemotherapy. No. I say to someone like yourself, the news is both good and bad. It’s good that [Woman: Something that can be done about it] We picked it up at this stage before it’s likely to be mischievous. Ah - It’s bad – it’s just you’re going to have to have a bit of surgery. [Woman: It’s got to have it done] and a little bit of radiotherapy.”

2) Woman's medical-related profession

The woman's medical-related profession may be one of the factors that influenced the information provided by the surgeon. The following is an example of how the surgeon, subsequent to the woman saying she was a nurse, asked the woman how much she understood about breast pathology and whether she understood the differences between an *in situ* cancer and invasive cancer.

Surgeon X/ Woman X (nurse): "Um – and let me explain. It's a type of tumour, but probably nothing that's going to be life threatening. But needs to have something done about it. [Woman: Righty oh. I'll just get my glasses] Yes, I'm sure you're not a pathologist. [Patient: I'm not, I'm a nurse] You're a nurse, so – how much do you know about breast pathology? [Woman: Nil] No, alright. [Woman: I'm a midwife] A midwife, alright. Do you know the difference between a true cancer and what we call carcinoma in situ? [Woman: I've heard of it, but I ..] I've heard of it. [Woman: I wouldn't know, yeah – you explain it to me] Let me explain it – Yep. Now, this is a picture of a breast."

b) Woman's communication within the consultation

The woman's communication within the consultation, that is, the woman's informational cues including direct questions and indirect statements immediately preceding information-giving by the surgeon was examined as a possible factor to explain why surgeons communicated differently with different women.

The woman's communication within the consultation may be one of the factors that influenced whether the surgeon told the woman the name of her diagnosis. The following is an example of how the surgeon explained the name of the diagnosis to the woman who suggested "DCIS" as her diagnosis. The surgeon did not provide this information to another woman who did not suggest the name of her diagnosis.

Surgeon X/ Woman X (woman suggests the name of the diagnosis):
“What the biopsy has shown is this is what we call, um, a
precancerous lesion. Or what we actually call it is an in situ [later in
consultation]: So it’s not an invasive cancer. As we call it, but it is an
abnormality. [Woman: ah – D...C...I...S] That, that’s right.
[Woman: That, so, it is that?] That is, that is exactly what it is
[Woman: What it is] The technical term that we use, we call it Ductal
Carcinoma in Situ [Woman: carcinoma in situ, yep, yeah].”

The woman’s communication within the consultation may also be one of the factors that influenced whether the surgeon provided information about the differences between invasive breast cancer and DCIS. The following is an example of how the surgeon told the woman who asked “Would you expect this would be able to cure it?” that her condition “shouldn’t cause you to die because it’s still all trapped within the duct”. The surgeon did not provide this information to another woman who did not ask a similar question.

Surgeon X/ Woman X (woman asks a question): [Woman: Would you
expect this would be able to cure it?] “Well, if it was the, if is just
Ductal Carcinoma in situ, then really the aim is to, um, completely
cure you, yes. Um, that condition, um, you know, shouldn’t cause you
to die because it’s still all trapped within the duct.”

The woman’s communication may also be one of the factors that influenced the information provided by the surgeon about the uncertainty about the natural history of DCIS. The following is an example of how the surgeon provided information about the uncertainty about the natural history of DCIS, including a statistic about the percentage of women who would develop invasive breast cancer if left untreated, to the woman who asked “How do you know that it will grow?”. The surgeon did not provide this information to another woman who did not ask a similar question.

Surgeon X/ Woman X (woman asks a question): “And usually it is a tube just lined by one row of nice happy cells. If as you go down through a row of changes that can happen inside the ducts you get to where you are and it can eventually go on to turn into proper breast cancer. We think if you keep following this sort of step ladder down the line here. [Woman: How do you know that it will grow?] Right. We don’t know 100% that that will happen. We know that in about 50 to 60% of people who have what you’ve got, which I’m about to describe, if it’s left alone it will turn into a breast cancer, proper breast cancer.”

The following is another example of how the surgeon discussed the uncertainty about knowing which DCIS women would develop invasive breast cancer with the woman who asked “If I don’t do the operation?”. The surgeon did not provide this information to another woman who did not ask a similar question.

Surgeon X/ Woman X (woman asks a question): “So we are actually quite pleased here in Breast Screening - if we have to find something, this is a good thing to find. Because we can treat it, and it’s early – it’s not proper breast cancer – so we’ve caught it before it’s turned into something significantly more nasty. [Woman: Yes Yes. If I don’t do the operation?] If you don’t – OK yeah [Woman: What happens?] What would happen. Unfortunately we don’t know how to predict which people who have this problem will definitely get breast cancer and which will not.”

The woman’s communication may also be one of the factors that influenced the information provided by the surgeon about the woman’s prognosis. The following is an example of how the surgeon provided information about the woman’s prognosis immediately after statements from the woman such as “if it’s something that can be dealt with?” and “no reoccurrence of that, yes”. In this example the surgeon only consulted with one woman as part of the study as no comparison data were available.

Surgeon X/ Woman X (woman asks indirect questions): [Woman: So that's, that's – no, well. Well I suppose it is a shock, but um, but if it's something that can be dealt with?] "It's something that can be easily dealt with [Woman: Well] And we know that the – um – in terms of following up patients who have a proper treatment [Woman: Yes] 99% have been cured with the correct treatment. [Woman: Yes] Yeah. So, so 99% will have no further trouble. [Woman: No reoccurrence of that, yes] Exactly, or [Woman: Of that particular spot] or chance of it becoming cancer, that's right, yeah, that particular spot. [Woman: Yes. Right]"

4 Discussion

This study provides an indepth description of doctor-patient communication about DCIS by examining audio-taped initial diagnostic consultations (n=30). This study is particularly important because no published study to date has examined how doctors actually communicate about DCIS to women. The study demonstrates that important aspects of the diagnosis, prognosis and treatment of DCIS are often poorly communicated to women and identifies eight factors that are likely to impede women's understanding about their diagnosis.

First, the study found that the important differences between DCIS and invasive breast cancer were inadequately communicated to women. In most consultations surgeons did not explicitly tell women that their diagnosis cannot cause death unlike 'breast cancer as we commonly understand it'. Surgeons may be concerned that discussing death with women may increase their anxiety. However, there is evidence that women with DCIS want to know whether they can die from their diagnosis and that this is a key area of misunderstanding among women with DCIS.^{26,27,28}

Furthermore, in 40% of consultations surgeons did not explain to women that DCIS cannot spread to other parts of the body unlike 'breast cancer as we commonly understand it'. In addition, some surgeons described the woman's diagnosis as "*still*

confined to the breast” rather than confined to the *ducts* and “*at a stage before it has begun to spread beyond the breast*” rather than at a stage where it *cannot spread*.

Inadequate or inaccurate communication about the incapacity of DCIS to spread beyond the ducts may partly explain the inaccurate perceptions among women with DCIS about their breast disease metastasizing.^{26,27,29} A cross-sectional survey (described in *Chapter 2*) found that women with DCIS want more information about whether their breast disease can metastasize and that women who did not know that DCIS could not metastasize were more likely to worry about dying from DCIS, resulting in an unnecessary psychological burden for women with DCIS.³⁰

Second, the study found that surgeons used potentially ambiguous terms and euphemisms to describe DCIS and invasive breast cancer. Ambiguity is common in cancer consultations and euphemistic expressions are commonly used in an attempt to soften the blow, but sometimes health professionals are unaware that they have conveyed the wrong meaning.³¹ A substantial proportion of patients have been shown to misunderstand phrases often used in cancer consultations.^{32,33} Guidelines for breaking bad news to patients include providing information simply and honestly and avoiding euphemisms as an important step when delivering a cancer diagnosis.³⁴ The present study found that in 40% of consultations surgeons described the diagnosis as an ‘early breast cancer’ or ‘early cancer’. Although in most of these consultations women were also told they had DCIS or ductal carcinoma in situ, phrases such as “*it’s a very early form of breast cancer*” and “*I’m afraid I need to tell you that it did show an early cancer*” may be understood incorrectly by women as indicating early invasive breast cancer.

Furthermore, some of the terms and euphemisms surgeons used to describe invasive breast cancer may be understood incorrectly by women as indicating metastatic breast cancer. Therefore, surgeons’ attempts to reassure women that they do not have invasive breast cancer by telling women, for example, “*It hasn’t turned into a full blown cancer*”, may result in some women incorrectly interpreting that their diagnosis is early invasive breast cancer that has not developed into metastatic breast cancer rather than DCIS that has not developed into early invasive breast cancer, as intended by surgeons. Even the terms “*invasive cancer*” or “*non-invasive breast cancer*” could be potentially

misunderstood by women if not further defined in terms of the capacity of the diagnosis to spread and cause death. In addition, the euphemisms used in some consultations to convey the message that DCIS cannot spread or cause death such as “[DCIS] *never hurt anybody*”; and invasive breast cancer can spread or cause death such as “[*invasive breast cancer*] *is more dangerous*” may not clearly convey to women the important differences between DCIS and invasive breast cancer.

Although this study found that in most consultations surgeons explained that DCIS is a precursor to invasive breast cancer the use of potentially ambiguous terms and euphemisms to describe DCIS and invasive breast cancer may have resulted in some women understanding incorrectly that their diagnosis is a precursor to metastatic breast cancer rather than early invasive breast cancer. The study also found that in two thirds of consultations surgeons explained that the aim of treatment is to remove the DCIS to help prevent invasive breast cancer from developing in the breast. However, the use of potentially ambiguous terms and euphemisms to describe DCIS and invasive breast cancer may have resulted in some women understanding incorrectly that the aim of treatment is to remove early invasive breast cancer to help prevent metastatic breast cancer.

Third, the study found that surgeons used multiple terms within the same consultation to describe the diagnosis, such as ‘early breast cancer’, ‘pre-cancer’ and ‘ductal carcinoma in situ’. This finding is consistent with the results of a cross-sectional survey with women with DCIS (described in *Chapter 2*). In this survey, women reported that multiple terms were used during consultations to describe their diagnosis and that they were confused by being told that they had ‘cancer’ and that they did not have ‘cancer’ within the same consultation: “*I was told that I had both breast cancer and that I had a pre-cancer, it seemed contradictory and I found this was a bit confusing.*”

Fourth, the study found that surgeons often did not reassure women with DCIS in the *initial* communication in the consultation that they did not have ‘breast cancer as we commonly understand it’. The structure of the consultation has been shown to be important in determining how patients understand and recall information.^{35,36} In the present study, some surgeons told women that they did not have ‘cancer’ in their *initial*

communication in the consultation followed by an explanation of how the diagnosis differed from invasive breast cancer. In contrast, other surgeons told women that they had “*early breast cancer*”, “*early changes of breast cancer*” or “*a special type of breast cancer*” in their initial communication in the consultation but subsequently (either immediately following or much later in the consultation) told *some* women how their diagnosis differed from invasive breast cancer. Explaining to women in the initial communication that they do not have ‘cancer’ (as we commonly understand it) may provide more reassurance to women and be less likely to cause misunderstanding than if this message is explained to women at a later time in the consultation.

Fifth, the study found that women were not told their diagnosis in 20% of consultations. Surgeons may be concerned that the term “ductal carcinoma in situ” is too complex for some women to understand or that the term “carcinoma” may confuse or alarm some women. However, patients have a legal and moral right to accurate information about their diagnosis and the doctor has a duty to disclose information to the patient.³⁴ In addition, the communication of the diagnosis is frequently delivered by more than one health professional,³¹ and omission of the diagnosis by one health professional is likely to cause confusion if this information is communicated by another health professional. Furthermore, inadequate information is likely to undermine the development of a trusting doctor-patient relationship.³⁷

Sixth, the study found that the uncertainties involved in the natural history of DCIS were frequently not communicated to women with DCIS. Although only some women with DCIS will develop invasive breast cancer if they are not treated,² in only half of the consultations in the present study did surgeons convey this information to women. Inadequate clinician communication about the uncertainty of DCIS progression to invasive breast cancer may explain why a cross-sectional survey (described in *Chapter 2*) found that only 19% of women with DCIS were aware that not all women with DCIS would develop invasive breast cancer if left untreated. Although it is not possible to accurately predict which women with DCIS will go on to develop invasive breast cancer,^{3,38} in the present study in less than 20% of consultations did surgeons explain to women the uncertainty about knowing which women would develop invasive breast cancer if left untreated. Furthermore, the evidence estimating the proportion and

timeframe of DCIS progression to invasive breast cancer is uncertain as no direct observations are possible due to the current standard of surgical removal of the DCIS.² The evidence is derived from studies of cases of DCIS that were initially misdiagnosed as benign lesions and were treated with biopsy alone.² The best estimates are that 14% to 53% of untreated DCIS may progress to invasive breast cancer over a period of ten years or more.² However, the present study found that surgeons used different statistics to describe the proportions and percentages of women who would develop invasive breast cancer if untreated and some statistics used were higher than the best estimates. In only one consultation did the surgeon convey to the woman the uncertainty about these statistics. The study also found that in less than 20% of consultations did the surgeons explain to women the uncertainty about knowing how long after the diagnosis invasive breast cancer would develop in the breast if left untreated.

The uncertainty about whether a particular woman with DCIS will develop invasive breast cancer complicates treatment decision-making for women and doctors. Perhaps the lack of disclosure about the uncertainty surrounding the natural history of DCIS found in the present study was due to doctors' concern that disclosing this uncertainty would affect patients' willingness to have treatment. Surgeons may also be reluctant to disclose uncertainty due to apprehension that it may undermine patient trust, that patients will perceive them as inadequate or ineffective, or that it will increase patients' anxiety.^{39,40} There is little empirical evidence about the impact on patients of communicating uncertainty, such as when the medical evidence is unknown or unknowable, or regarding the optimal strategies for communicating uncertainty to patients, as discussed in *Chapter 3*. However, many ethicists and researchers urge doctors to express uncertainty to patients to promote realistic patient expectations, enable informed consent, and ensure a greater level of shared decision-making.^{41,42,43,44,45,46,47} Furthermore, a recent qualitative study found that most women with DCIS wanted more honest information about their diagnosis including information about the uncertainties relating to DCIS.⁴⁸

Seventh, the study found that surgeons did not explain to women that invasive breast cancer may be found during surgery in 40% of consultations. Surgeons may be concerned that telling women that invasive breast cancer may be found during surgery

will cause additional, perhaps unnecessary, distress to women. However, recommendations for breaking bad news such as a cancer diagnosis include preparing the patient for the possibility of bad news as early as possible in the diagnostic process, such as when the patient requires further tests.³⁴ Provisional diagnoses and decisions that allow for changing priorities and circumstances over time may also assist doctors in managing one area of uncertainty with patients.^{49,50,51} Furthermore, a study measuring the effect of various communication opportunities on patients' psychological morbidity found that patients had lower anxiety about a cancer diagnosis if the doctor prepared the patient for this possibility.⁵²

Eighth, the study found that surgeons did not often use communication behaviours that may assist women in understanding the information provided about DCIS such as checking women's understanding and inviting questions. The study found that surgeons did not verbally check women's understanding about their diagnosis in any of the consultations. Although surgeons in a few consultations asked women if they understood the information, and surgeons may have assessed patients' non-verbal (for example, facial expression and posture) or paraverbal cues (for example, auditory pitch and tone) indicating patient understanding or surgeons may have provided indirect cues asking patients if they understood the information, surgeons did not explicitly ask women to explain their understanding of how DCIS differs from invasive breast cancer. Checking patients' understanding about their diagnosis is considered an important step in breaking bad news as it allows doctors' the opportunity to correct misunderstandings.^{34,53} However, asking patients *if* they understand is not enough as patients often overestimate their comprehension.³² Given that women may experience difficulty in understanding how DCIS differs from invasive breast cancer, misunderstandings may be minimised if women's comprehension is verified by asking them *what* they have understood, rather than *if* they understand.³² In addition, in only 10% of consultations did surgeons invite questions from women specifically about the diagnosis, such as how DCIS differs from invasive breast cancer, or questions relating to the natural history of DCIS. Surgeons were more likely to invite general questions from women after discussing issues relating to treatment during closure of the consultations. Given that the primary aim of the initial diagnostic consultation is to explain the diagnosis to women, inviting questions specifically about the diagnosis will

help ensure that women understand their diagnosis before considering treatment options. Any confusion about DCIS and its implications is likely to make decisions about treatment more difficult for women.

However, the study also identified communication techniques that surgeons used during consultations that may have reassured women with DCIS and assisted them in understanding their diagnosis. The study found that surgeons explained to women in most consultations that their condition was potentially ‘curable’ with treatment or that treatment resulted in a low risk of recurrence of DCIS or invasive breast cancer. Surgeons in some consultations also provided reassurance to women while maintaining honesty by explaining that “*the news is both good and bad*”. Furthermore, surgeons may have minimised women’s anxiety while communicating about the possibility of detecting invasive breast cancer by explaining that this possibility was not very likely, “*Very occasionally we find that once we’ve removed that area there is a little bit of invasive cancer within what we’ve taken out. Um – that’s pretty unusual.*” and reassuring women that at this stage they did not have invasive breast cancer, “*But, um, from what we’ve got so far on the biopsies, all they’ve seen is the Ductal Carcinoma in Situ.*” This technique is consistent with a recent study of audio-taped cancer consultations which found that doctors could deliver information honestly without diminishing opportunities for hope by following uncertain or bad news by relatively better news in the practice of ‘pairing information’.⁵⁴

The study also found that surgeons used diagrams, such as printed or drawn diagrams or women’s mammogram, in 70% of the consultations. In-consultation diagrams have been shown to facilitate patients’ understanding and recall of information.^{55,56,57} In the present study, diagrams were used to facilitate women’s understanding of the breast tissue pathology and to help explain how DCIS differs from invasive breast cancer.

4.1 Limitations of the study

This study was limited by the use of a small and select sample. Surgeons were recruited from urban BreastScreen assessment centres. Given that half of all diagnoses of DCIS occur at BreastScreen assessment centres,²³ this sample of surgeons may have more

experience in communicating a diagnosis of DCIS to women and perhaps these surgeons communicate more effectively about DCIS than surgeons outside BreastScreen. Research is required to examine the communication of the diagnosis of DCIS outside the BreastScreen program and in rural BreastScreen assessment centres. Given that the communication of the diagnosis is frequently delivered by more than one health professional,³¹ research is also required to examine the communication of the diagnosis of DCIS by other health professionals such as oncologists, general practitioners and nurses. Further research would also enable additional reliability testing and refinement of the coding system for the analysis of communication about DCIS.

There is evidence that women with DCIS from culturally and linguistically diverse (CALD) backgrounds have poorer knowledge about their diagnosis.^{58,59} This study hypothesizes that doctors may communicate differently about DCIS to women who are less proficient in English. Research is required to examine how doctors communicate with women with DCIS from CALD backgrounds, and to develop recommendations about how to tailor communication to their specific needs. In addition, there is a need to examine how doctors communicate with women with DCIS from Aboriginal or Torres Strait Islander backgrounds given cultural differences in interpretation and experience of illnesses such as breast cancer.^{60,61}

This study was limited to exploring the communication of key aspects of the diagnosis and prognosis of DCIS that were most relevant to the initial diagnostic consultation. Given that the purpose of the initial diagnostic consultation is to explain the diagnosis of DCIS to women, the study examined the initial explanations of the diagnosis and natural history of DCIS and reassurance of women, and not on communication tasks likely to occur in subsequent consultations, such as effectively communicating about treatment, follow-up and support. Thus, information-giving behaviours and communication behaviours to facilitate understanding of the information provided to women were included while women's involvement in treatment decision-making and whether clinicians elicited and responded to emotion and referred women to support services were not included. There is a need to explore issues such as treatment decision-making and support more relevant to subsequent consultations in women with DCIS.

Doctor-patient communication involves a complex interaction between doctors and patients.^{10,14,20,62} The present study found differences in the way that surgeons communicated the diagnosis and prognosis of DCIS with different women. Possible factors that may explain these differences were raised in this study and included the woman's ethnicity, prognostic factors, medical-related profession, and communication within the consultation. Further research with a larger sample is required to examine variation in surgeon communication about DCIS with different women and the reasons for any variation in communication. The present study also found differences between surgeons in their communication of the diagnosis and prognosis of DCIS. However, the study did not further explore these differences or hypothesise about what factors may have contributed to the variation between surgeons in their communication about DCIS. Further research with a larger sample is required to examine the differences between doctors in their communication about DCIS and whether factors such as age, gender, doctors' level of clinical knowledge and experience, and doctors' level of intolerance to uncertainty influence any variation in communication about DCIS. Such research would provide a greater understanding of doctor-patient communication about DCIS.

The poor communication demonstrated by surgeons in this study may reflect the challenges in communicating the complexities of DCIS; a lack of awareness among doctors that some terms and euphemisms used to describe DCIS and invasive breast cancer may be confusing to women and convey to women the wrong meaning about their diagnosis; a lack of confidence among doctors about how to communicate uncertainty with patients; doctors' intolerance of uncertainty; fear among doctors that communicating uncertainty to women with DCIS will increase their anxiety or affect their willingness to have treatment; or a lack of understanding even among doctors about the nature of DCIS. There is a need for further research to investigate the reasons why important aspects of the diagnosis, prognosis and treatment of DCIS are often poorly communicated to women. Such research on barriers to open communication could provide vital information to guide future interventions to improve communication.

This study identifies factors that may impede woman's understanding about their diagnosis and demonstrates the need to improve doctor-patient communication about

DCIS. The study also suggests additional communication techniques that could be incorporated into the *Key Communication Elements (DCIS)* such as avoiding the use of potentially ambiguous terms and euphemisms (with examples of terms and phrases to avoid), and delivering information about DCIS honestly without diminishing opportunities for hope by following uncertain or bad news by relatively better news.

4.2 Practice implications

This study demonstrates that important aspects of the diagnosis, prognosis and treatment of DCIS are often poorly communicated to women and identifies the need to develop communication techniques and strategies to improve practice. Possible techniques to improve practice derived from this study include the following:

- Tell women with DCIS the most important information first, that is, that women with DCIS do not have breast cancer as we commonly understand it.
- Provide information to women about *how* DCIS differs from invasive breast cancer by first, communicating that DCIS cannot spread (describing DCIS as “*confined to the ducts*” rather than confined to the “*breasts*” and at a stage where “*it cannot spread*” rather than “*before it has begun to spread*”); and second, communicating that a woman cannot die from DCIS unless it has developed into invasive breast cancer.
- Tell women with DCIS the name of their diagnosis, that is, ductal carcinoma in situ (DCIS).
- Provide information to women with DCIS about the uncertainties surrounding DCIS progression to invasive breast cancer in terms of first, that not all women with DCIS will develop invasive breast cancer if they are not treated; second, that it is not known which women with DCIS would develop invasive breast cancer if left untreated; thirdly, that the exact proportion of women with DCIS who would develop invasive breast cancer if left untreated is not known; and

fourth, that it is not known how long after the DCIS diagnosis invasive breast cancer would develop if left untreated.

- Avoid the use of potentially ambiguous terms and euphemisms to describe DCIS and invasive breast cancer, in particular avoiding the use of descriptions of DCIS such as *“early breast cancer”* *“early changes of breast cancer”* or *“a special type of breast cancer”*, the use of descriptions of invasive breast cancer such as *“full blown cancer”* and *“a more progressive form of breast cancer”*, and the use of phrases such as *“[DCIS] never hurt anybody”* and *“[invasive breast cancer] is more dangerous”*.
- Be aware that potentially ambiguous terms and euphemisms may result in women with DCIS understanding incorrectly that their diagnosis is a precursor to metastatic breast cancer rather than invasive breast cancer, and that the aim of treatment is to remove early invasive breast cancer to prevent metastatic breast cancer rather than to remove the DCIS to prevent invasive breast cancer from developing in the breast.
- Verify women’s comprehension about the diagnosis by asking them *what* they have understood about how DCIS differs from invasive breast cancer.
- Encourage women with DCIS to ask questions about their diagnosis and prognosis.
- Deliver information honestly without diminishing opportunities for hope by following uncertain or bad news by relatively better news, for example, explain to women with DCIS that *“the news is both good and bad”*; and explain to women during the initial diagnostic consultation that there is a possibility of detecting invasive breast cancer during surgery while reassuring women that at this stage they did not have invasive breast cancer and that the chance of detecting invasive breast cancer is very small.

A potentially effective strategy for implementing the techniques recommended in this study may be to incorporate them into communication skills training programs for clinicians about how to communicate effectively about DCIS. There is evidence that communication skills training programs can improve doctors' communication skills, and increase their confidence in communicating effectively with patients.^{63,64}

Communication skills training programs could also inform clinicians about the most current evidence and understanding about DCIS. Examples of effective and poor communication in the present study could be used in communication skills training programs as they provide empirical examples of real interactions that could enable doctors to hear *how* they interact with patients. Future research is required to develop and evaluate communication skills training programs for clinicians about how to communicate effectively about DCIS.^{64,65}

4.3 Conclusions

This study is the first study to date that examines how doctors actually communicate about DCIS to women. This study demonstrates the challenges in communicating the complexities of DCIS and identifies factors that are likely to impede women's understanding about their diagnosis. Furthermore, this study demonstrates the need to improve doctor-patient communication about DCIS and suggests possible techniques and strategies to improve practice.

This study creates a deeper understanding of the communication about DCIS vital for developing interventions to improve doctor-patient communication. Effective communication about DCIS is the key to promoting better understanding about DCIS and increasing the well-being of women with DCIS.

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Chapter 5

Development and pilot testing of a communication aid (CA) to assist clinicians to communicate the diagnosis and treatment of ductal carcinoma in situ with women

Appendix 5.1

De Morgan SE, Butow PN, Lobb EA, Price MA, Nehill C. Development and pilot testing of a communication aid to assist clinicians to communicate with women diagnosed with ductal carcinoma in situ (DCIS). Support Care Cancer 2011;19:717-723.

Appendix 5.2

DCIS communication aid (CA): Understanding ductal carcinoma in situ (DCIS) and deciding about treatment. National Breast and Ovarian Cancer Centre (NBOCC) 2009 ISBN Print: 978 1 74127 149 2 Available online at Cancer Australia: www.canceraustralia.gov.au

1 Introduction

There is evidence that women's confusion and misunderstanding about how DCIS differs from invasive breast cancer is compounded by inadequate information about DCIS (*see Chapter 2*), and poor communication about DCIS in medical consultations (*see Chapter 4*). However, there are no published studies to date about interventions designed to improve doctor-patient communication and women's understanding about DCIS.

Communication aids are an emerging technique that have been shown to improve doctor-patient communication and patients' understanding of information^{1,2,3,4} and may assist in communication about DCIS. Communication aids present evidence-based information in written, numerical and graphical formats.^{1,4} Communication aids such as question prompts sheets, consultation summaries, audio-tapes, tailored print information, evidence-based pamphlets and computer based programs have been shown to improve patient's knowledge, increase question-asking, and information recall.^{1,2,5} Communication aids are more likely to increase patients' understanding if they are interactive and if the information is tailored to the individual.⁴

Unlike communication aids, decision aids are designed to help people make specific and deliberative choices by presenting evidence on benefits and harms of the options, clarifying values, and guiding patients in the decision-making process.⁶ Decision aids such as evidence-based pamphlets, audio-booklets, videos, and computer based programs have been shown to improve patients' knowledge, reduce difficulty with decision-making, and increase participation in the decision-making process.^{6,7,8} A communication aid rather than a decision aid was considered to be the most appropriate intervention for this study as the intervention aimed to improve women's understanding about their diagnosis and treatment rather than guide women in treatment decision-making. The literature demonstrates the benefits and feasibility of communication and decision aids that require direct physician involvement during consultations with patients.^{9,10}

The objective of this study is to undertake a pilot test of a DCIS Communication Aid (CA) developed to assist clinicians to communicate with women diagnosed with DCIS and to improve women's understanding about their disease, prognosis and treatment. Specifically, the study aims to assess: (i) women's and clinicians' perceptions of the CA in terms of their satisfaction with the content, design and diagrams in the CA; and (ii) perceptions of the benefits of the CA, its impact on doctor-patient communication, and the feasibility of using the CA during clinical consultations. Pilot testing of the CA was considered to be an essential first step before testing the impact of the CA in a randomised control trial.

2 Methods

The DCIS Communication Aid (CA) was developed; evaluated by women diagnosed with DCIS and clinicians who used the CA in their consultations; and revised based on the evaluation with women and clinicians. Ethics approval was obtained from the Cancer Council Victoria, Human Research Ethics Committee and the University of Sydney, Human Research Ethics Committee. The study was funded by the National Breast and Ovarian Cancer Centre (NBOCC), Sydney, Australia. This section describes firstly, how the CA was developed (2.1) and secondly, pilot testing of the CA (2.2).

2.1 Development of the CA

Given the lack of published guidelines for the development of communication aids, the consensus guidelines for developing decision aids were adapted.¹¹ This involved identifying the need, feasibility and objectives for the communication aid (see above), and employing a theoretical framework to guide its development and evaluation.

2.1A *Theoretical framework to guide the development of the CA*

The Ottawa Decision Support Framework (ODSF)¹² is an evidence-based, practical theory for guiding patients making health or social decisions. It uses a three-step process to: a)

assess client and practitioner determinants of decisions to identify decision support needs; b) provide decision support tailored to client needs; and c) evaluate the decision-making process and outcomes. It is based on concepts from general psychology, social psychology, decision analysis, decisional conflict, social support, and economic concepts of expectations and values. The ODSF has been used to guide the development and evaluation of patient decision aids. The ODSF was adapted for this pilot study, to include: a) assessing the determinants of patient knowledge and doctor-patient communication such as patient and clinician characteristics; b) providing tailored information support to patients by means of a communication aid (CA) used in consultations with patients; and c) evaluating the outcomes of the information support in terms of patients' and clinicians' perceptions of whether the CA would improve patient knowledge and doctor-patient communication (*as illustrated in Table 5.1*).

Table 5.1: Framework to guide development and evaluation of the CA in a pilot study

Assess determinants of patient knowledge and doctor-patient communication	Provide information and communication support (CA)	Evaluate information and communication support
<p><i>Patient characteristics:</i> age; gender; ethnicity; date of diagnosis; type of treatment</p> <p><i>Clinician characteristics:</i> gender; type of medical specialty; public or private hospital practice; years in practice; number of DCIS women per month</p>	<p><i>Information support:</i></p> <ul style="list-style-type: none"> • diagnosis of DCIS • prognosis • treatment options • risk of recurrence after treatment • emotional support <p><i>Communication support:</i></p> <ul style="list-style-type: none"> • clinician tailors information to the patient's disease features • diagrams to assist clinician communication and patient understanding 	<p><i>Patients' and clinicians' perceptions of:</i></p> <ul style="list-style-type: none"> • improvement in patient knowledge • improvement in doctor-patient communication

2.1B *Content of the CA*

The information in the CA is based on the *Key Communication Elements (DCIS)* developed in *Chapter 3*. The *Key Communication Elements (DCIS)* aim to assist doctors to effectively communicate about important aspects of the diagnosis, prognosis, treatment and support of women with DCIS. They are based on the best available evidence from the literature concerning the experiences of women diagnosed with DCIS (limited to descriptive studies) and the literature about doctor-patient communication (including descriptive and intervention studies largely with cancer patients).

Key Communication Elements (DCIS) were selected as relevant to the development of the CA if they concerned information-giving behaviours related to the diagnosis, prognosis, treatment and support of women with DCIS. Elements were excluded that were related to communication behaviours such as inviting questions, checking women's understanding, eliciting and responding to emotion, and assessing women's social support. In addition, the CA was not intended to guide women in treatment decision-making and therefore did not include information about the side effects of treatment, or assist in clarifying women's values and concerns about treatment options.

Furthermore, the CA was not intended to address the information needs and preferences of women with low education and women from culturally and linguistically diverse (CALD) backgrounds. The study assessed clinicians' overall perceptions of whether the CA would be appropriate for these women to assess the need to develop adapted versions of the CA in future research.

Table 5.2 outlines the *Key Communication Elements (DCIS)* that informed the content of the CA.

Table 5.2: Key Communication Elements (DCIS) that informed the content of the CA

Key Communication Elements (DCIS)	
<i>A. Effectively communicating a diagnosis of ductal carcinoma in situ (DCIS)</i>	
1.	Reassure the woman that she <u>does not</u> have breast cancer as we commonly understand it, that is, invasive breast cancer
2.	Tell the woman she has ductal carcinoma in situ or DCIS
3.	Explain how DCIS differs from invasive breast cancer
<i>B. Effectively communicating about DCIS prognosis</i>	
1.	Explain the natural history of DCIS
2.	Explain the uncertainties relating to the natural history of DCIS: <ul style="list-style-type: none"> i. Explain that not all women with DCIS will develop invasive breast cancer if they are not treated, that is, some women with DCIS will never develop breast cancer if they are not treated ii. Explain the uncertainty about knowing which DCIS women would develop invasive breast cancer iii. Explain the uncertainty about the exact proportion of DCIS women who would develop invasive breast cancer iv. Explain the uncertainty about knowing how long after the DCIS diagnosis invasive breast cancer would develop
3.	Explain the provisional nature of prognostic information: <ul style="list-style-type: none"> i. Explain that more information will be obtained when the pathologist examines the breast tissue removed during surgery ii. Explain that the information in the pathology report will affect decisions about treatment
4.	Explain the currently known DCIS prognostic factors: <ul style="list-style-type: none"> i. Explain that the pathology report reports on the features of the DCIS such as the size, nuclear grade, surgical margins and whether there are any areas of invasive breast cancer or microinvasion ii. Explain the features of a woman's DCIS which make her more or less likely to develop invasive breast cancer eg high nuclear grade, larger size, positive surgical margins, and microinvasion increase the risk of developing invasive breast cancer and DCIS coming back in the breast iii. Explain that current research hopes to discover more precise prognostic factors

continued next page

Key Communication Elements (DCIS)

C. Effectively communicating about treatment for DCIS

1. Explain the aim and importance of treatment:
 - i. Explain that treatment for DCIS aims to remove the DCIS to help prevent invasive breast cancer from developing in the breast
 - ii. Explain that invasive breast cancer is a serious condition that can spread and cause death
 2. Reassure the woman of an excellent prognosis after treatment: Explain that most women diagnosed and treated for DCIS will not develop invasive breast cancer or DCIS again in that breast
 3. Present the treatment options of breast conserving surgery, mastectomy, radiotherapy and hormonal therapies.
 4. Discuss the treatment options:
 - i. Explain the aims of the treatment options
 - ii. Explain the features of a woman's DCIS which make her more or less likely to benefit from breast conserving surgery or mastectomy
 - iii. Explain the features of a woman's DCIS which make her more or less likely to benefit from radiotherapy (ie the benefit of radiotherapy for women with small, low grade DCIS is less than for women with larger, higher grade DCIS)
 - iv. Explain whether hormonal therapies may benefit women with DCIS (including the uncertainty); and the potential side effects of hormonal therapies
 - v. Explain the situations in which one or more lymph nodes may need to be removed
 - vi. Explain that chemotherapy is not used to treat DCIS
 5. Explain the risk of DCIS and invasive breast cancer recurrence after treatment(s):
 - i. Explain the risk of DCIS and invasive breast cancer recurrence after breast conserving surgery with and without radiotherapy, after mastectomy using the most recent data
 - ii. Tailor information to the individuals' characteristics where possible
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E. Effectively providing support for women with DCIS

1. Avoid minimising the impact of the diagnosis and treatment of DCIS: Acknowledge the impact of diagnosis and treatment including coping with the uncertainty about whether women may develop invasive breast cancer or the DCIS may come back.
 2. Provide information about where to get additional emotional support and information.
-

2.1C *Design and format of CA*

The CA was designed as a colour booklet as this format has been shown to be acceptable and low cost.^{1,13} The CA included visual aids such as diagrams and illustrations to enhance patient understanding and recall of information.^{4,6,14} The diagrams were produced by a graphic designer specifically commissioned for the study. The CA was written for a readability of an early high school level similar to that used in other consumer resources developed by the NBOCC and as recommended by health communication experts.¹⁵

The risk communication literature highlights the importance of tailoring information to the individual characteristics of each patient.^{16,17,18,19,20} The CA was designed to be tailored to the disease characteristics (for example, grade, and size of the DCIS lesion) and risk factors (for example, age) of each woman by the clinician marking key features at relevant points. A combination of visual (100 dot frequency diagrams), numerical (percentages and n/100) and word-based (low, medium, high) representations of risk were used as they have been shown to improve understanding of information.^{21,22,23} The risk information was presented in terms of absolute risk rather than relative risk; related rather than unrelated base rates; and horizontal rather than vertical pictographs as these features have been shown to decrease confusion.^{22,24,25} Information about aspects of DCIS which increase the risk of developing invasive breast cancer, and which suggest a greater benefit from mastectomy or radiotherapy, were presented in weigh scale diagrams, a format used in previous research.¹³ The CA also included a final page where clinicians could write notes for the woman.

2.1D *Review of the CA by senior health researchers*

The CA was reviewed by senior health researchers specialising in the development of communication aids and decision aids for cancer patients at the Centre for Medical Psychology & Evidence-Based Decision-Making at the University of Sydney to ensure that the content and design of the CA was appropriate and optimised patient understanding.

2.1E *How to Use guide*

A *How to Use* guide was developed for clinicians to assist them in using the CA in clinical consultations (*see Appendix 5.3*). The CA was not intended to be used like a script but rather to complement the clinicians' usual communication style. Clinicians were instructed to use the diagrams and information where relevant during the consultation. Clinicians were also instructed to give the woman the CA at the end of the consultation to take home with her.

2.2 Methodology for pilot testing the CA

2.2A *Participants and procedure*

Thirty women with DCIS diagnosed between September 2006 and August 2007 who had participated in an earlier study conducted by The Cancer Council Victoria and had expressed a willingness to be contacted about further research, were invited into this study. Women were eligible if they were considered by their treating surgeon to read and speak sufficient English to complete consent forms and participate in a telephone interview and were not excluded due to ill-health. Women were purposively selected to represent a range of age, education and treatment categories. Eligible women were sent a letter of invitation to the study (*see Appendix 5.4*), a study information sheet (*see Appendix 5.5*) and a consent form (*see Appendix 5.6*). Women who provided written consent were mailed the CA and participated in a telephone interview. There was no follow-up of women who did not return consent forms. Interviews were audio-taped and transcribed. Interviews with 18 women were conducted, after which informational redundancy was reached (no new information or themes emerged from the data)^{26,27} and no further recruitment was undertaken.

Clinicians (n=10) actively treating women with DCIS were identified by the National Breast and Ovarian Cancer Centre (NBOCC) and invited verbally to participate in the study. Interested clinicians (n=8) were sent a letter of invitation to the study (*see Appendix 5.8*), a study information sheet (*see Appendix 5.5*), a consent form (*see Appendix 5.9*), the

CA (see Appendix 5.2), a *How to Use* guide (see Appendix 5.3) and a written survey (see Appendix 5.10). Clinicians (n=7) who provided written consent were given verbal instructions about how to use the CA, asked to use the CA in two consultations, and completed a written survey.

2.2B Measures

A structured interview schedule to evaluate the CA was developed for women with DCIS (see Appendix 5.7). Items in the interview schedule included 16 statements with *disagree* or *agree* response options and four open questions. The statements were framed positively and negatively to discourage automatic responses from participants. The interview assessed satisfaction with the content, diagrams and design of the CA, and perceived benefits and emotional impact of the CA. Suggestions for improvement were also elicited. Women were also asked specifically to comment on descriptors of DCIS used in the CA, including that DCIS is: a) a risk of developing into breast cancer; and b) not breast cancer as we commonly think of breast cancer.

The structured interview schedule was adapted for clinicians and designed as a written survey (see Appendix 5.10). In addition to the issues explored with women, clinicians were asked about barriers and facilitators to using the CA, its impact on consultation length and style, and whether it would be inappropriate for subgroups of women such as women with low education levels. Some open questions elicited further feedback about the CA and suggestions for improvement.

Demographic data were gathered from the women (ie age, educational status, first language, date of diagnosis and treatment received) and clinicians (ie gender, medical specialty; public or private hospital practice; years in practice; number of women with DCIS clinicians consulted with on average per month; and whether clinicians used the CA in initial diagnostic consultations at a mammographic screening service and/or subsequent consultations (either prior to or after the woman's surgery) outside the mammographic screening service.

2.2C *Data Analysis*

Data were entered into the Statistical Package for Social Sciences (SPSS). Descriptive statistics were used to describe interview and survey responses. The qualitative data from open questions were coded into themes and sub-themes using thematic analysis.^{26,27}

Following the coding by the author, the data within each code was discussed with her supervisors to increase the author's understanding of the data and to confirm that the codes were justifiable. Interviews with 18 women were conducted, after which informational redundancy was reached (no new information or themes emerged from the data) and no further recruitment was undertaken.

3 *Results*

3.1 *Pilot testing the CA with women diagnosed with DCIS*

3.1A *Sample*

The women (n=18) evaluating the DCIS CA were diagnosed 6 to 24 months prior to participation in the study, with the majority diagnosed 12 to 18 months prior to the study. Women's age ranged from 42 to 84 years, with an average age of 63. Sixty-one per cent of women had a tertiary qualification. All of the women had undergone surgery and 44% also had radiotherapy. Women were not asked what type of surgery they had received. All of the women spoke English as their first language. *Table 5.3* outlines the demographic and treatment related characteristics of the women participating in the study.

Table 5.3: Demographic and treatment-related characteristics of women with DCIS who participated in the pilot study (n=18)

<i>Age</i>	
Mean	63 years (SD 10.5)
Median	64 years
Range	42-84 years
<i>Date of diagnosis</i>	
Median	12-18 months prior to study
Range	6-24 months prior to study
<i>English as first language</i>	18 (100%)
<i>Education</i>	
Some primary or secondary school	1 (6%)
School certificate (Year 10)	5 (28%)
HSC (Year 12)	1 (6%)
College/ University	11 (61%)
<i>Treatment for DCIS</i>	
Surgery	18 (100%)
Surgery and radiotherapy	8 (44%)
Hormonal therapy	0 (0%)

3.1B Women's perceptions of the CA

3.1Bi Women's perceptions of the benefits of the CA

Table 5.4 (see Page 369) outlines women's perceptions of the benefits of the CA in terms of improving women's understanding about DCIS and improving communication with clinicians. All or most women felt the CA would help women to understand their diagnosis; the natural history of DCIS; their treatment options and their prognosis after treatment; and would assist in communication between doctor and patient.

“It’s good that someone has something simple that they can look at and can see easily where they are at. And it’s helpful for the doctor to be able to use a tool like this and maybe can highlight and mark the things that are applicable.”

“I found the whole guide very straightforward, very easy to understand and very helpful.”

Women reported being confused and uninformed about how DCIS differs from invasive breast cancer and what would happen if the DCIS was left in the breast, and reflected on how the CA would assist in reducing confusion.

“It wasn’t even pointed out to me the difference between invasive (breast cancer) and DCIS. So you’re up in the air. If the doctors had this it would be very handy.”

“It was good to read that DCIS can’t spread to the lymph glands because that was something I was worried about.”

However, a few women still felt confused about aspects of their DCIS, even after reading the CA.

“I’m wondering if you ignored it, would it become invasive. I’ve always been confused about that and even with this guide I’m still confused.”

“It says here that it cannot spread outside of the breast to other parts of the body. So how can it become breast cancer?”

Women’s confusion was compounded by the different explanations they received from health professionals about their diagnosis.

“I’ve had one doctor say to me yes it is breast cancer, another say it’s early breast cancer and another say it’s not breast cancer but it could develop into breast cancer....I am still not 100% sure at this stage whether I have had breast cancer or not.”

One woman suggested that the CA would help women to formulate questions in the consultation.

“I wish I’d got it [the CA] sooner, so I’d know what questions to ask. It just helps to ask all the questions.”

Another woman suggested that the CA may assist in shared decision-making about treatment.

“Something like this brings you into the decision-making process. It isn’t just the doctor or the specialist making the decision for you.”

3.1Bii Women’s perceptions of the emotional impact of the CA

Most women thought that the CA would not increase women’s anxiety, as shown in *Table 5.4 (see Page 369)*.

“I don’t think it was threatening or anything. It was just really simple, which is good. I’ll show it to my husband too.”

Some women felt the CA should contain more reassuring and positive information about the DCIS diagnosis such as reassurance that they cannot die from DCIS unless it develops into invasive breast cancer, and that treatment for DCIS is very successful.

“I think a bit more reassurance just popped in different places.”

“I’d rather have a more positive slant. People need some hope.”

Table 5.4: Women’s (n=18) perceptions of the benefits and emotional impact of the CA

		Women’s perceptions of the CA
		n (%)
A	The DCIS diagnosis	
	<i>The Aid would help women to understand:</i>	
i	their diagnosis	18 (100%)
ii	the difference between DCIS and invasive breast cancer	17 (94%)
iii	the natural history of DCIS, that is, what will happen if the DCIS was left in the breast	15 (83%)
B	Treatment for DCIS	
	<i>The Aid would help women to understand:</i>	
i	why treatment is recommended for DCIS	18 (100%)
ii	their treatment options	18 (100%)
iii	their prognosis after treatment, that is, how likely it is that the DCIS will come back or invasive breast cancer will develop after treatment	17 (94%)
C	Communication with clinicians	
i	<i>The Aid would help women to</i> communicate with their doctor about DCIS	18 (100%)
D	Emotional impact of the CA	
i	<i>The Aid would not</i> make women too anxious	17 (94%)
Missing (n=0)		

3.1Biii Women's perceptions of the content in the CA

Most women liked the content of the CA.

"There's not too much information, there's just the right amount."

Most women liked the description of DCIS as "not breast cancer as we commonly think of breast cancer".

"It [the CA] had things written in it that I really liked to read, such as DCIS is not breast cancer as we commonly understand it. A statement like that is really helpful. Because I wrestled with whether it was cancer or not."

However, a few women found this description of DCIS difficult to understand.

"Why do they say it's not breast cancer when the cells have changed. Why aren't they still cancer? If it's cancer it's cancer whether it's invasive or not. When they do say it's not cancer and you tell people it's not cancer, then they say well why have you got your breast off? To me it's very confusing. It's the same question that I have had all the way along."

Most women liked the description of DCIS as a risk of developing into breast cancer, except one woman who found this concept difficult to understand.

"Being diagnosed with DCIS puts you at increased risk of being subsequently diagnosed with invasive breast cancer. That just leaves a question mark in my mind as to why. It's a bit of an open statement."

One woman suggested that the CA should include information about the risk of developing invasive breast cancer for women in the general population.

“I would like to see what the chances of getting invasive cancer are for women who have not had DCIS. I’d like a comparison with women who have never had breast cancer so you could see how much worse off you are. I’d like to see how much worse off I am than a normal person.”

One woman suggested that the CA should include the risk of developing invasive breast cancer in the other breast for women diagnosed with DCIS.

“Something on the risk of getting DCIS in the other breast is something that could have been put in. That’s something I am concerned about.”

3.1Biv Women’s perceptions of the diagrams and design of the CA

Table 5.5 outlines women’s perceptions of the diagrams in the CA. Most women liked the diagrams in the CA and felt that the diagrams helped them to understand their diagnosis.

“What I found was that it gave you a better understanding of DCIS itself and the pictures give you a better idea of where it is and explains things better for you.”

“It puts your mind at rest because with the diagrams you can see everything much clearer.”

Most women liked the weighing scale diagrams in the CA and felt they clarified the information in the consultation.

“What I found most interesting were the [weighing scales] pictures on pages 4 and 5. It clarified what the doctor had said.”

“The scales were explicit and easy to understand. It’s not only words. Putting it into a diagrammatic form is more useful.”

However, a few women either did not understand the weighing scale diagrams or thought they were difficult to read.

“I can’t see the point in having scales. I don’t like the way it is laid out. I just don’t find it easy to read.”

A few women also thought the diagram of the milk ducts and the lobules in the breast could be clearer.

“I didn’t understand the diagrams on the front page. All the little milk ducts. Are they all joined together making up the lobule? I didn’t know what a lobule was. It wasn’t clear.”

Table 5.5: Women’s perceptions of the diagrams in the CA

		n (100%)
i	I like the diagrams of DCIS and invasive breast cancer in the breast in the CA	16 (89%)
ii	I like the diagrams of breast conserving surgery and mastectomy in the CA	18 (100%)
iii	I like the diagrams of weighing scales in the CA	15 (83%)
iv	I like the risk diagrams in the CA	16 (89%)

Most women liked the design of the CA.

“It’s attractive looking, nice colours...it’s very tastefully done.”

One woman suggested that the CA should include a cover page for privacy.

“I’d put another cover over the front...It’s not something you want everyone else to see.”

3.2 Pilot testing the CA with clinicians

3.2A Sample

Table 5.6 outlines the gender and practice related characteristics of participants. Five breast surgeons and two radiation oncologists from four major cities in Australia participated in the study. Four clinicians were female and three clinicians were male. Clinicians’ experience in medical practice ranged from 10-22 years, with the average number of years being 15 years. Most clinicians (71%) currently practiced in the public hospital system only. Clinicians consulted with, on average, five DCIS patients per month. Two clinicians used the CA during initial diagnostic consultations at a mammographic screening service. Most clinicians (n=5) used the CA in subsequent consultations, either prior to or after the woman’s surgery.

Table 5.6: Gender and practice related characteristics of clinicians (n=7)

Gender	<i>Female</i>	4 (57%)
	<i>Male</i>	3 (43%)
Medical specialty	<i>Breast surgeon</i>	5 (71%)
	<i>Radiation Oncologist</i>	2 (29%)
Years in practice	<i>Mean</i>	15 years
	<i>Range</i>	10-22 years
Number of DCIS patients per month	<i>Mean</i>	5 women
	<i>Range</i>	1-12 women
Practice residence	<i>Sydney, NSW</i>	3 (43%)
	<i>Melbourne, Victoria</i>	2 (29%)
	<i>Brisbane, Queensland</i>	1 (14%)
	<i>Perth, WA</i>	1 (14%)
Missing (n=0)		

3.2B *Clinicians' perceptions of the CA*

3.2Bi *Clinicians' perceptions of the benefits of the CA*

Table 5.7 (see Page 376) outlines clinicians' perceptions of the benefits of the CA in terms of improving women's understanding about DCIS. All or most clinicians felt the CA would help women to understand their diagnosis, the natural history of DCIS, their treatment options and their prognosis after treatment, and would assist them to communicate with women newly diagnosed with DCIS.

"I think it does supplement what I am doing."

“It’s a good way to structure consultations, going through page by page.”

All the clinicians said that they liked the content of the CA. Most clinicians used all of the information and diagrams in the CA in their order of publication. Most clinicians reported that they would use the CA regularly and most clinicians reported that they thought women with DCIS would like the CA. Most clinicians reported that the CA would not make their consultations too long or change their consultation style. One clinician thought that the CA would actually shorten consultations.

“The scales and risk diagrams will shorten consultation.”

3.2Bii Clinicians’ perceptions of the emotional impact of the CA

Most clinicians thought that the CA would not increase women’s anxiety. One clinician was unsure about whether the CA would make women too anxious.

“The Aid could make women too anxious.”

Table 5.7: Clinicians' (n=7) perceptions of the benefits and emotional impact of the CA

		Clinicians' perceptions of the CA
		n (%)
A	The DCIS diagnosis	
	<i>The Aid would help women to understand:</i>	
i	their diagnosis	7 (100%)
ii	the difference between DCIS and invasive breast cancer	7 (100%)
iii	the natural history of DCIS, that is, what will happen if the DCIS was left in the breast	6 (86%)
B	Treatment for DCIS	
	<i>The Aid would help women to understand:</i>	
i	why treatment is recommended for DCIS	6 (86%)
ii	their treatment options	7 (100%)
iii	their prognosis after treatment, that is, how likely it is that the DCIS will come back or invasive breast cancer will develop after treatment	6 (86%)
C	Communication with clinicians	
i	<i>The Aid would help women to</i> communicate with their doctor about DCIS	7 (100%)
D	Emotional impact of the CA	
i	<i>The Aid would not</i> make women too anxious	6 (86%)
Missing (n=0)		

3.2Biii Clinicians' perceptions of the content in the CA

All the clinicians liked the content of the CA.

“Overall I thought it was good.”

Most clinicians approved of DCIS being described as “not breast cancer as we commonly think of breast cancer”. One clinician thought that this description of DCIS could be problematic.

“I think describing it as “not breast cancer” can be problematic as other clinicians may use the word “cancer”, plus it is a malignant diagnosis and may make things like travel insurance invalid if not correctly declared.”

Most clinicians also approved of DCIS being described as “a risk of developing into breast cancer”. However, one clinician thought that this description of DCIS was inappropriate and that DCIS should be re-conceptualised as a precursor to invasive breast cancer, a description that the clinician thought was more in keeping with current thinking about DCIS and its relationship to invasive breast cancer.

“DCIS is not a risk factor, it is a precursor, therefore the statement that it is putting you at risk is not appropriate.”

Two clinicians suggested that only a brief summary about hormonal therapies should be included in the CA given that most women with DCIS are not offered hormonal therapies and that the evidence about the benefit of hormonal therapies is still uncertain for women with DCIS.

“As far as I know clinicians are not using Tamoxifen so much. I don’t think it’s widely accepted (as a treatment). Some studies show a reduced risk of recurrence but at present it’s not a treatment that is widely used, because of potential side effects. Best for patient to discuss with doctor. Would “dampen down” this page. Not have the risk diagrams as that only refers to one study and there are others that don’t show the same results. It’s still controversial.”

“Most of our patients do not get hormone Rx [treatment].”

One clinician suggested that there should be greater emphasis about why treatment is recommended for DCIS with this information being included on the first page in addition to the second page of the CA.

“A sentence could be added to Page 1 ‘Treating the DCIS will prevent a cancer forming in most cases’ (or words to that effect).”

One clinician suggested that the information about necrosis in the CA be deleted as it was not useful in addition to the grade of the DCIS in treatment decision-making.

“Necrosis – I think this is not useful in decisions.”

One clinician suggested including adding age as a factor in the weighing scale diagrams in the CA about the risk of developing invasive breast cancer and who would benefit most from radiotherapy, consistent with current research.

“I would have added age as a factor as younger women have higher rates of recurrence than older women. Usually there is more of a push to offer radiotherapy to younger women.”

One clinician suggested including space on the last page of the CA for clinicians to add local phone numbers for additional support for women diagnosed with DCIS.

“Would be good to have a few spaces to add in local numbers eg local care coordinators.”

3.2Biv Clinicians’ perceptions of the diagrams and design of the CA

Table 5.8 outlines clinicians’ perceptions of the diagrams in the CA. Most clinicians liked the diagrams in the CA.

“The Aid is visually powerful.”

However, there were mixed views about the risk diagrams in the CA. Some clinicians liked the risk diagrams, while others thought them too complex.

“The scales and risk diagrams are great – best feature.”

“The risk diagrams are too complex.”

“It was confusing in the way it was laid out.”

Two clinicians thought that average risk statistics were not useful in discussions with women about risk of recurrence after treatment.

“The numbers (percentages, which are an average) may not apply to the patient you are seeing – depending on their risk factor it could be higher or lower.”

The clinicians suggested using risk statistics for women from higher and lower risk groups rather than using average risk statistics. One clinician suggested combining the invasive and DCIS recurrences to reduce the number of diagrams used in this section of the CA.

“I would suggest putting DCIS and invasive occurrences on the same 100 patients and but in different colours and compare high grade and low grade or high risk and low risk.”

Table 5.8: Clinicians’ perceptions of the diagrams in the CA

		n (100%)
i	I like the diagrams of DCIS and invasive breast cancer in the breast in the CA	7 (100%)
ii	I like the diagrams of breast conserving surgery and mastectomy in the CA	6 (86%)
iii	I like the diagrams of weighing scales in the CA	6 (86%)
iv	I like the risk diagrams in the CA	4 (57%)

Most clinicians liked the format of the CA. One clinician thought that the CA would be better designed as a flip chart to assist in finding relevant information.

“I would prefer something I could just dip into the relevant bits – eg a flip chart.”

3.2Bv Clinicians’ perceptions of the appropriateness of the CA for all women

Most clinicians reported that the CA was not appropriate for women with only primary school education.

“I thought only highly intelligent patients would cope with the scales diagrams.”

“Also patients that don’t understand numbers well [is a barrier].”

Most clinicians also reported that the CA was not appropriate for women from culturally and linguistically diverse (CALD) backgrounds. One clinician thought the CA could be used with women who did not speak English as their first language if an interpreter was also available.

“I tried it with a woman from a non-English speaking background and totally lost her and had to start all over again.”

“Language is a barrier.”

3.2Bvi Clinicians’ perceptions of the type of consultation most suited to using the CA

A few clinicians reported that the CA was best used during consultations after surgery due to the amount and type of information included in the CA. For example, the features of the woman’s DCIS used to determine risk recurrence were usually detected during surgery.

“Too detailed for first consultation.”

“I found the real problem was using it pre-op. There was too much information and not all information was relevant to the woman’s specific circumstances.”

“Best used after first operation (pre-op only core biopsy info).”

3.3 Revision of the CA

The CA was revised based on the results of the evaluation with women and clinicians.

3.3A *Revision of the content of the CA*

Changes in content were made to the CA in the following six key areas:

1) Reassurance for DCIS women

More reassuring and positive information about the DCIS diagnosis was included in the revised CA, including reassuring women that they cannot die from DCIS unless it develops into invasive breast cancer, and that treatment for DCIS is very successful.

2) The DCIS diagnosis

Clearer information was included in the revised CA about the natural history (including the uncertainty) of DCIS; and why DCIS is not breast cancer as we commonly understand it. In addition, DCIS was re-conceptualised as a precursor to invasive breast cancer rather than ‘increasing the risk’ of being subsequently diagnosed with invasive breast cancer to prevent misunderstanding and to be in keeping with current thinking about DCIS and its relationship to invasive breast cancer.

3) Treatment for DCIS

A greater emphasis about the purpose of treatment was included in the revised CA with this information being included on the first and second page of the CA. In addition, information about hormonal therapies was reduced to a brief summary in the revised CA given that clinicians thought that detailed information was not highly relevant for women with DCIS.

4) *The prognosis of DCIS*

Age was included as a factor in the weighing scale diagrams in the revised CA about the risk of developing invasive breast cancer and who would benefit most from radiotherapy. The revised CA also included risk categories for developing a recurrence; simplification of risk diagrams by combining the invasive breast cancer and DCIS recurrences; and additional risk information including the risk of developing invasive breast cancer for women in the general population and the risk of developing invasive breast cancer in the other breast for women diagnosed with DCIS. Information about necrosis was not included in the revised CA.

5) *Support for women with DCIS*

The CA was revised to include space on the final page for clinicians to add the contact details for local support groups.

6) *How to use the CA*

The CA was revised to include information about how to use the CA (in addition to the *How to Use* guide).

3.3B *Revision of the format of the CA*

Changes in the format were also made to the CA and include the following: 1) simplifying the layout of risk information and risk dot diagrams about recurrence after treatment to increase women's understanding of risk information; 2) labelling the lobules and milk ducts in the breast diagram; and 3) including a cover page.

The CA was also revised to be more interactive with clinicians. The revised version was designed so that clinicians could tailor the information in the CA to the woman by a) *circling* the relevant features of the woman's DCIS in the diagrams of weighing scales; b)

circling the woman's risk category for recurrence: lower, intermediate and higher risk; and
c) *ticking* the boxes for relevant features associated with lower and higher risk.

Given adequate budget, it is also recommended that the CA be designed as a flipchart to make finding relevant information easier for clinicians.

3.3C *Revision of How to Use guide for clinicians*

The *How to Use* guide for clinicians was revised to provide clearer instructions to clinicians about how to use the CA (*see Appendix 5.3*). Clinicians were instructed to use the diagrams and information where relevant and in any order; and that they did not need to use all of the diagrams and information in the CA. Clinicians were made aware that the diagrams and information that they found useful would depend on whether they were using the CA during the initial diagnostic consultation or in subsequent consultations, either prior to or after the woman's surgery. Clinicians were also instructed to tailor the information in the CA to the patient by *circling* or *ticking* the relevant features of the woman's DCIS as described above.

4 Discussion

The pilot testing of the CA revealed that both clinicians and women diagnosed with DCIS thought that the CA would assist them to better communicate about DCIS and would help women to understand their diagnosis and treatment. This study also highlights the potential benefits of using communication aids with patients and shows the need for pilot testing of communication aids before being used in the intended setting or being tested in a randomised control trial.

Furthermore, the need to standardise practice via interventions such as communication aids is supported by the response of one clinician to the CA: "*I think describing it as "not breast cancer" can be problematic as other clinicians may use the word "cancer", plus it*

is a malignant diagnosis.” Given that DCIS cannot metastasize and cause death, it is debatable whether DCIS can really be considered a malignant lesion. The response of this clinician suggests that there may be a lack of understanding among doctors about the nature of DCIS. Further research is required to examine doctors’ understanding about what is currently known and not known about DCIS

4.1 Limitations of the study

This study was limited by the use of a small and select sample of clinicians and women with DCIS. A randomised control trial using a larger and more diverse sample is required to test the effectiveness of the CA in changing current communication practices and improving patient outcomes such as patient knowledge and quality of life in the short and long term.²⁸

Further research is also needed to evaluate the barriers to implementing the CA into routine practice;¹⁰ and to develop and evaluate strategies to ensure access and use of the CA in clinical practice.^{4,29} Schofield *et al* outline the stages for implementing evidence-based interventions and identify the most effective ways to disseminate an intervention so that it will be incorporated into routine clinical practice.²⁸ They also identify disseminating the intervention, and monitoring whether the intervention has been broadly adopted as important stages in implementing interventions.²⁸

Given that most clinicians reported that the CA was not appropriate for women with low education and from culturally and linguistically diverse (CALD) backgrounds, there is a need to develop and evaluate adapted versions of the CA for these women. Research suggests that developing and evaluating decision aids for patients with low education and literacy requires consideration of a wide range of linguistic aspects beyond the traditional focus on the readability of materials with testing in these populations.^{30,31} Similarly, research suggests that patients from CALD backgrounds have specific information needs and preferences, for example, women with DCIS from CALD backgrounds want to be provided with culturally appropriate information in their own language.³²

4.2 Practice implications

The CA is currently available in print and online for clinicians to use during their consultations with women diagnosed with DCIS: *Understanding ductal carcinoma in situ (DCIS) and deciding about treatment*. National Breast and Ovarian Cancer Centre (NBOCC) 2009 ISBN Print: 978 1 74127 149 2. Available online at Cancer Australia: www.canceraustralia.gov.au

The CA could also be incorporated into communication skills training programs for clinicians about how to communicate effectively about DCIS. There is evidence that communication skills training programs can improve doctors' communication skills, and increase their confidence in communicating effectively with patients.^{33,34} Future research is required to develop and evaluate communication skills training programs for clinicians about how to communicate effectively about DCIS.^{34,35}

4.3 Conclusions

This is the first communication aid developed for women diagnosed with DCIS. This study highlights that the DCIS Communication Aid is considered a valuable resource by clinicians and women. It is anticipated that the revised version of the CA will assist communication, promote better understanding about DCIS, and increase the well-being of women with DCIS.

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Discussion

1 Discussion

The incidence of ductal carcinoma in situ (DCIS) has increased substantially since the advent of widespread breast screening mammography.¹ Unlike invasive breast cancer, DCIS cannot metastasize and a woman cannot die from DCIS unless it develops into invasive breast cancer.² However, the natural history of DCIS is not well understood and it is currently not possible to accurately predict which women with DCIS will go on to develop invasive breast cancer.³ Clinicians are faced with unique communication challenges arising from the fact that DCIS is not an invasive cancer and that DCIS is “surrounded by a sea of uncertainty”.^{4,5} The *Discussion* will focus on describing the insights that this thesis provides about these communication challenges, and more widely, the communication challenges associated with non-invasive cancers and situations of uncertainty, such as when the medical evidence is unknown or unknowable and when doctors must make provisional diagnoses and decisions. The *Discussion* will also describe the implications of the findings of this thesis for future research.

1.1 The challenge of communicating about a non-invasive cancer

This thesis provides insight into the communication challenges specific to DCIS and non-invasive cancers that are increasingly being detected in this era of screening. An essential function of doctor-patient communication has been identified as information provision.⁶ Doctors must also ensure that information is provided in a way that it will be understood by patients.⁷ The challenge for clinicians is to communicate about non-invasive cancers in such a way that patients understand the important differences between a non-invasive cancer and an invasive cancer, that is, that a non-invasive cancer lacks the capacity to metastasize and cause death, unlike an invasive cancer. Using DCIS as an example, this thesis shows a lack of understanding among patients and poor communication from clinicians about the key differences between a non-invasive cancer and an invasive cancer. It also identifies strategies to improve doctor-patient communication and patients’ understanding about this issue.

This thesis provides evidence from a systematic review of the qualitative and quantitative evidence about the experiences of women with DCIS and a cross-sectional

survey of women with DCIS in Australia (*Chapters 1 & 2*) that there is confusion and misunderstanding among women with DCIS about how their diagnosis differs from invasive breast cancer. Women with DCIS are confused by whether they have ‘cancer’ that can result in death and overestimate their risk of local recurrence, metastases and dying from their disease. The cross-sectional survey of women with DCIS found, for example, that only 12% of women knew that DCIS cannot metastasize. The review also found that there is evidence that women from culturally and linguistically diverse (CALD) backgrounds particularly face difficulties in understanding the implications of a non-invasive cancer.

The review and the cross-sectional survey of women with DCIS (*Chapters 1 & 2*) shed some light on the potential consequences of women’s confusion and misunderstanding about their diagnosis. Inaccurate risk perceptions among women with DCIS are associated with higher levels of anxiety and ‘cancer-specific worry’. The cross-sectional survey of women with DCIS demonstrated, for example, that approximately half of women worried about their breast disease metastasizing and that worry about dying from their breast disease was significantly associated with not knowing that DCIS cannot metastasize.

Furthermore, it is critical that patients understand the implications of a non-invasive cancer so that they can make informed decisions about treatment. Patients must understand the important difference between the prevention goal of treatment for a non-invasive cancer and the therapeutic goal of treatment for an invasive cancer. However, there is a paucity of evidence about women’s knowledge about this issue. Qualitative studies with women with DCIS reported in the review found that some women experience difficulty understanding why they are recommended treatment options used to treat invasive breast cancer, especially a mastectomy, when they do not have ‘real’ breast cancer: “*It felt like they were using a sledgehammer to crack a nut*”. The cross-sectional survey of women with DCIS (*Chapter 2*) found that approximately half of women with DCIS experience high decisional conflict. High decisional conflict has been shown to result in delayed decision-making and feeling emotionally distressed by the decision.⁸ The review also demonstrates that women with DCIS from CALD backgrounds are more likely to choose a mastectomy even in situations when they are

recommended to have breast conserving surgery reflecting a lack of understanding about their diagnosis.

Meeting patients' information needs has been shown to increase understanding,⁹ and improve psychological adjustment and perceived quality of life.^{10,11,12} There is evidence from qualitative and quantitative studies reported in the review that women with DCIS want more written and verbal information about their diagnosis and prognosis. The cross-sectional survey of women with DCIS (*Chapter 2*) found, for example, that approximately half of women with DCIS would have liked more information about whether their breast disease could metastasize, one third would have liked more information about the type of breast disease they had, 44% would have liked more information about the chances of local recurrence after treatment, and one third would have liked more information about the chances of their breast disease metastasizing or dying from their breast disease if they did or did not have treatment. There is also evidence from the review that women with DCIS from CALD backgrounds want more information about their diagnosis and treatment in their first language.

Improved doctor-patient communication about DCIS is likely to increase women's understanding about DCIS and reduce women's distress. Although there are currently evidence-based recommendations for clinicians about how to effectively communicate with women diagnosed with invasive breast cancer¹³ there are no comprehensive evidence-based recommendations that outline for clinicians how to effectively communicate with women diagnosed with DCIS. This thesis therefore describes the first stage of development of recommendations, the *Key Communication Elements (DCIS)*, for clinicians about how to communicate with women diagnosed with DCIS (*Chapter 3*). While some of the recommendations developed for communicating with women with invasive breast cancer and patients in general are relevant to women with DCIS, the *Key Communication Elements (DCIS)* also address the communication challenges specific to DCIS, including the challenge of communicating about the important differences between DCIS and invasive breast cancer. The *Key Communication Elements* are based on the best available evidence from the literature about the experiences of women with DCIS (limited to descriptive studies) and the literature about doctor-patient communication (including descriptive and intervention

studies). However, there is currently no evidence of the effectiveness of the proposed recommendations with women with DCIS. Therefore, the *Key Communication Elements (DCIS)* cannot yet be considered the ‘gold standard’ for communication about DCIS.

There is a need to understand how clinicians currently communicate in practice about DCIS and whether there are gaps between ‘ideal’ and actual communication. This thesis sought to understand this issue by examining how and to what extent surgeons (n=13) communicate in accord with the *Key Communication Elements (DCIS)* during initial diagnostic consultations (n=30) at BreastScreen centres (government funded mammographic screening centres) in Victoria, Australia. The direct observation technique of audio-taping consultations was used as it has been shown to be a valuable research tool contributing to greater understanding of doctor-patient communication in many contexts,^{14,15,16,17,18,19,20,21} and in particular providing the opportunity to understand the complex interaction between doctors and patients.^{22,23,24,25}

Understanding how clinicians communicate in practice is vital to guide future interventions to improve communication. This study is particularly important because no published study to date has examined how clinicians actually communicate about DCIS to women during consultations.

Some of the communication challenges highlighted in the audiotape study (*Chapter 4*) have been widely recognised as challenges that doctors experience in communicating with cancer patients generally. The literature demonstrates that communication about prognostic information is often inadequate,^{26,27,28} and that doctors sometimes have poor communication skills and infrequently use some behaviours that may facilitate understanding of the information provided such as inviting questions and checking patients’ understanding.^{29,30,31} The literature also demonstrates that ambiguity is common in cancer consultations, euphemistic expressions are commonly used in an attempt to soften the blow,³² and that a substantial proportion of patients misunderstand phrases often used in cancer consultations.^{29,33}

The audiotape study provides additional insight into the communication challenges specific to DCIS and more widely to non-invasive cancers. The study found that the important differences between DCIS and invasive breast cancer were often inadequately

communicated to women. For example, in most consultations surgeons did not explicitly tell women that their diagnosis cannot cause death, unlike invasive breast cancer; and in 40% of consultations surgeons did not explain to women that DCIS cannot spread to other parts of the body, unlike invasive breast cancer. In addition, some surgeons described the woman's diagnosis as "*still confined to the breast*" rather than confined to the *ducts* and "*at a stage before it has begun to spread beyond the breast*" rather than at a stage where it *cannot spread*. The study also found that surgeons did not often reassure women with DCIS in the *initial* communication in the consultation that they did not have invasive breast cancer. The structure of the consultation has been shown to be important in determining how patients understand and recall information.^{6,9} Explaining to women in the initial communication that they do *not* have 'cancer as we commonly understand it' may provide more reassurance to women and be less likely to cause misunderstanding than if this message is explained to women at a later time in the consultation.

The audiotape study also provides examples of potentially ambiguous terms and euphemisms surgeons used to describe DCIS and invasive breast cancer that may impede women's understanding about their diagnosis. In particular, DCIS was described as "*early breast cancer*" (in 40% of consultations), "*early changes of breast cancer*", or "*a special type of breast cancer*"; and invasive breast cancer was described as "*full blown cancer*" and "*a more progressive form of breast cancer*". Ambiguous terms and euphemisms may result in women with DCIS incorrectly interpreting that their diagnosis is a precursor to metastatic breast cancer rather than invasive breast cancer; and that the aim of treatment is to remove early invasive breast cancer to prevent metastatic breast cancer rather than to remove the DCIS to prevent invasive breast cancer from developing in the breast.

The audiotape study also found that surgeons used multiple terms within the same consultation to describe the diagnosis, such as 'early breast cancer', 'pre-cancer' and 'ductal carcinoma in situ'. This finding is consistent with the results of the cross-sectional survey with women with DCIS reported in this thesis. In this survey, women reported that multiple terms were used during consultations to describe their diagnosis and that they were confused by being told that they had 'cancer' and that they did not

have ‘cancer’ within the same consultation: *“I was told that I had both breast cancer and that I had a pre-cancer, it seemed contradictory and I found this was a bit confusing.”*

The audiotape study also found that women were not told their diagnosis in 20% of consultations. Surgeons may be concerned that the term ‘ductal carcinoma in situ’ is too complex for some women to understand or that the term ‘carcinoma’ may confuse or alarm some women. However, patients have a legal and moral right to accurate information about their diagnosis and the doctor has a duty to disclose information to the patient.³⁴ In addition, the communication of the diagnosis is frequently delivered by more than one health professional,³⁵ and omission of the diagnosis by one health professional is likely to cause confusion if this information is communicated by another health professional. Furthermore, inadequate information is likely to undermine the development of a trusting doctor-patient relationship.³⁶

The audiotape study suggests that interventions are needed to improve practice. There is evidence that clinical practice guidelines can be effective in changing the process of care and health outcomes.³⁷ However, there is also evidence that guidelines alone will not improve care.³⁷ Communication aids and decision aids are emerging techniques that have been shown to improve doctor-patient communication and patients’ understanding of information.^{38,39,40,41,42} In this thesis, a DCIS communication aid (CA) was developed and pilot tested to assist clinicians to communicate the diagnosis and treatment of DCIS (*Chapter 5*). This study is particularly important because there is no published study to date about interventions designed to improve doctor-patient communication and women’s understanding about DCIS. The CA is based on the *Key Communication Elements (DCIS)* and is intended to be used by clinicians during their consultations with women with DCIS. The pilot study of the CA revealed that both clinicians and women diagnosed with DCIS thought that the CA would assist them to better communicate about DCIS and would help women to understand their diagnosis and treatment. The CA is currently available in print and online at Cancer Australia (www.canceraustralia.gov.au). Communication aids, such as the CA, and decision aids may also assist clinicians to communicate with patients about other non-invasive cancers.

1.2 The challenge of communicating about uncertainty

The second challenge for clinicians is communicating about uncertainty with patients. Many ethicists and researchers urge doctors to express uncertainty to patients to promote realistic patient expectations, enable informed consent, and ensure a greater level of shared decision-making.^{43,44,45,46,47,48,49} Furthermore, helping patients ‘manage uncertainty’ has been identified as a key function of doctor-patient communication.^{50,51} Managing uncertainty involves providing information to patients to both reduce uncertainty and inform patients about irreducible uncertainty.^{52,53} Managing uncertainty also involves helping patients to emotionally cope with uncertainty.^{54,55}

This thesis provides insight into the challenge of communicating about two sources of uncertainty. First, the central uncertainty of the progression of a non-invasive cancer to an invasive cancer, and more widely, the uncertainty related to situations when the medical evidence is unknown or unknowable; and second, the uncertainty related to the initial diagnosis of a non-invasive cancer, and more widely, the uncertainty related to the provisional nature of diagnostic and prognostic tests. This thesis demonstrates poor communication from clinicians about both sources of uncertainty. This thesis also identifies strategies to improve doctor-patient communication and patients’ understanding about these sources of uncertainty.

There is general consensus, derived from the available laboratory and clinical data, that DCIS is a direct precursor to invasive breast cancer.^{5,56} However, not *all* DCIS will develop into invasive breast cancer.² Why and how often DCIS progresses to invasive breast cancer, the precise biologic pathway(s) between DCIS and invasive breast cancer, whether any subtypes of DCIS are more likely to progress than others, and how long after the DCIS diagnosis invasive breast cancer would develop is not well understood.^{57,58,59} The best estimates are that 14%-53% of untreated DCIS may progress to invasive breast cancer over a period of ten years or more.² The lack of evidence about the progression of DCIS to invasive breast cancer is due to the inability to directly observe the natural history due to the current standard of surgical removal of DCIS.⁶⁰ The central uncertainty for women diagnosed with DCIS is the inability to know

whether their DCIS will progress to invasive breast cancer or the time interval in which invasive breast cancer will occur if left untreated.

Furthermore, uncertainty is involved in the initial diagnosis of DCIS. A woman is usually diagnosed with DCIS after stereotactic core biopsy of the breast tissue under local anaesthesia.⁶⁰ However, stereotactic core biopsy may miss invasive breast cancer in about 15% of women initially diagnosed with DCIS.^{56,61} This means that a proportion of women who were initially diagnosed with DCIS will be diagnosed with invasive breast cancer after surgery.

Although knowledge of the uncertainty about the progression of DCIS to invasive breast cancer is needed for truly informed treatment decision-making, the review reported in this thesis found a paucity of evidence about women's knowledge of this uncertainty or the impact of this uncertainty on women with DCIS. The cross-sectional survey of women with DCIS suggests that women with DCIS have poor knowledge of the uncertainty about DCIS progression to invasive breast cancer. The study found that only 19% of women knew that not *all* women with DCIS would develop invasive breast cancer if untreated. Furthermore, little is known about women's knowledge of the uncertainty involved in the initial diagnosis of DCIS.

Improved doctor-patient communication about the uncertainties related to DCIS is likely to increase women's understanding of these issues. However, there is little empirical evidence about the optimal strategies for communicating uncertainty to patients, in particular the optimal strategies for communicating the uncertainty in situations when the medical evidence is unknown or unknowable. In contrast, much more is known about the communication of risk such as the communication of probabilities related to, for example, the benefits and harms of medical interventions.^{62,63,64,65,66}

The *Key Communication Elements (DCIS)* developed in this thesis includes recommendations about communicating uncertainty about the progression of DCIS to invasive breast cancer. However, the recommendations are based on an ethical

imperative to disclose uncertainty to patients rather than on evidence about the optimal strategies clinicians should use for communicating this uncertainty to patients.

There is also little empirical evidence about the optimal strategies for communicating the uncertainty related to the provisional nature of diagnostic and prognostic tests. Researchers have suggested ways to assist doctors to acknowledge this source of uncertainty with patients, such as making provisional diagnoses and decisions that allow for changing priorities and circumstances over time; planning for contingencies by providing appropriate if/then statements concerning situations requiring further action; avoiding slippage into general reassurance from a particular test result; and avoiding the creation of the myth of certainty.^{67,68,69} Therefore, the *Key Communication Elements (DCIS)* includes recommendations about communicating to women with DCIS the provisional nature of diagnostic and prognostic tests and that very occasionally invasive breast cancer may be found during surgery. This recommendation is also consistent with recommendations for breaking bad news that include preparing the patient for the possibility of bad news such as a cancer diagnosis as early as possible in the diagnostic process, such as when the patient requires further tests.³⁴ Furthermore, a study measuring the effect of various communication opportunities on patients' psychological morbidity found that patients had lower anxiety about a cancer diagnosis if the doctor prepared the patient for this possibility.⁷⁰

There is also little empirical evidence about the optimal strategies that clinicians should use during consultations to help patients 'manage uncertainty'. Although it is evident that patients need information to help reduce their perceived uncertainty,^{54,55} it is not clear whether cognitive-behavioural strategies and extensive psychosocial support for uncertainty should be provided during routine clinical care or if specialised psychological interventions are necessary.⁵⁰ Based on the evidence from interventions designed to help women with early invasive breast cancer and men with prostate cancer manage uncertainty,^{54,55,71,72,73,74} basic recommendations for helping women with DCIS manage uncertainty were incorporated into the *Key Communication Elements (DCIS)*. The recommendations include enabling women's 'positive reappraisal' of the meaning of the diagnosis, for example, by telling women "*this diagnosis does not signal death*"; allowing and encouraging women to express their concerns and feelings about any areas

of uncertainty and responding with empathy; and encouraging the woman to utilise her social support system.

There is a need to understand how and to what extent clinicians currently communicate uncertainty to patients, in particular the uncertainty related to situations when the medical evidence is unknown or unknowable and the uncertainty related to the provisional nature of diagnostic and prognostic tests. Understanding how clinicians communicate about these sources of uncertainty in practice is vital to guide future interventions to improve communication. This thesis sought to understand this issue by examining how surgeons communicate about the uncertainty of the progression of DCIS to invasive breast cancer and the uncertainty involved in the diagnosis of DCIS during audiotaped initial diagnostic consultations at BreastScreen centres. This study is particularly important because no published study to date has examined how and to what extent clinicians actually communicate about the uncertainties related to DCIS.

The audiotape study demonstrates that the central uncertainty of the progression of DCIS to invasive breast cancer is often inadequately communicated to women. For example, in only half of the consultations did surgeons explain to women that not all women with DCIS will develop invasive breast cancer if they are not treated; in less than 20% of consultations did surgeons explain to women that it is not known which women would develop invasive breast cancer if left untreated; in only one consultation did the surgeon explain to the woman that the exact proportion of women with DCIS who would develop invasive breast cancer if left untreated is not known; and in less than 20% of consultations did surgeons explain to women that it is not known how long after the DCIS diagnosis invasive breast cancer would develop if left untreated.

The audiotape study also found that surgeons did not explain to women in 40% of consultations that invasive breast cancer may be found during surgery. However, surgeons in this study who did disclose to women the possibility of an invasive breast cancer being detected during surgery demonstrated a technique that may minimise women's anxiety while acknowledging this uncertainty. Surgeons explained to the woman that the possibility of detecting an invasive breast cancer during surgery was not very likely and reassured the woman that at this stage she did not have invasive breast

cancer. This technique is consistent with a recent study of audio-taped cancer consultations which found that doctors could deliver information honestly without diminishing opportunities for hope by following uncertain or bad news by relatively better news in the practice of ‘pairing information’.¹⁸

The poor communication about the uncertainties related to DCIS demonstrated in this study suggests that interventions are needed to improve practice. The DCIS communication aid (CA) was developed and pilot tested to assist clinicians to better communicate about DCIS (as discussed above). The CA includes information about the central uncertainty of the progression of DCIS to invasive breast cancer and the provisional nature of prognostic information such as nuclear grade and size of the lesion. However, the CA did not include information about the possibility of detecting invasive breast cancer during surgery as this was considered to be a particularly sensitive issue that was best communicated by the woman’s clinician during the consultation and requiring strategies to help patients manage this uncertainty. The pilot study of the CA revealed, as stated above, that both clinicians and women diagnosed with DCIS thought that the CA would assist them to better communicate about DCIS and would help women to understand their diagnosis.

Communication aids, such as the CA, and decision aids may also assist clinicians to communicate with patients in other situations about the uncertainty related to the medical evidence. Elwyn *et al* developed a quality criteria framework for decision aids which outlines that information should be included in decision aids about the quality and strength of the evidence.⁷⁵ Communication aids and decision aids may also assist clinicians to communicate with patients in other situations about the uncertainty related to the provisional nature of diagnostic and prognostic tests.

1.3 Future research

This thesis demonstrates that research is required in two important areas. Firstly, there is a need to understand the reasons why key aspects of the diagnosis, prognosis and treatment of DCIS may be poorly communicated to women. Possible reasons for poor communication about DCIS such as a lack of understanding even among clinicians

about the nature of DCIS; or a lack of awareness about the potential ambiguity of particular euphemisms and terms used during consultations; or a fear among clinicians that communicating uncertainty may undermine patient trust,⁷⁶ that patients will perceive them as inadequate or ineffective,⁷⁷ that it will increase patients' anxiety,⁷⁸ and that it will affect patients' willingness to have treatment, need to be explored in future research. Such research on barriers to open communication could provide vital information to guide future interventions to improve communication.

Secondly, there is a need to develop interventions to assist clinicians to communicate about DCIS, and more widely, to assist clinicians to communicate about non-invasive cancers and situations of uncertainty, in particular the uncertainty related to situations when the medical evidence is unknown or unknowable and the uncertainty related to the provisional nature of diagnostic and prognostic tests. Clinical practice guidelines may be an effective strategy for improving doctor-patient communication and health outcomes for patients.³⁷ Further stages of development of the *Key Communication Elements (DCIS)* could be conducted to develop rigorous evidence-based clinical practice guidelines for communicating about DCIS such as establishing a multidisciplinary group of women with DCIS, clinicians, and researchers to oversee the development of the recommendations and review the evidence supporting the recommendations; and to conduct an extensive public consultation process involving members of the relevant professions and women with DCIS.⁷⁹

Further stages of development of the *Key Communication Elements (DCIS)* should also include research evaluating the optimal strategies for communicating about the uncertainties related to DCIS and helping women with DCIS cope with these uncertainties. Such research could also provide important information necessary for developing optimal strategies for communicating about the uncertainty related to the medical evidence and the uncertainty related to the provisional nature of diagnostic and prognostic tests, and helping patients manage these sources of uncertainty.

Communication aids^{38,40} and decision aids⁴² have also been shown to improve doctor-patient communication and patients' understanding of information. In this thesis, a DCIS Communication Aid (CA) was developed and pilot tested with women with DCIS

and clinicians. A randomised control trial using a larger and more diverse sample is required to test the effectiveness of the CA in changing current communication practices and improving patient outcomes such as patient knowledge and quality of life in the short and long term. There is also a need to develop and evaluate adapted versions of the CA for women with DCIS with low education and literacy, and women with DCIS from Aboriginal or Torres Strait Islander and CALD backgrounds.

Another potentially effective intervention that could incorporate the DCIS Communication Aid (CA) and the recommendations in the *Key Communication Elements (DCIS)* is a communication skills training program for clinicians.^{37,80} There is evidence that communication skills training programs can improve doctors' communication skills, and increase their confidence in communicating effectively with patients.^{80,81} Communication skills training programs could also inform clinicians about the most current evidence and understanding about DCIS. Examples of effective and poor communication in the study of audio-taped initial diagnostic consultations could be used in communication skills training programs as they provide empirical examples of real interactions that could enable doctors to hear *how* they interact with patients. Future research is required to develop and evaluate communication skills training programs for clinicians about how to communicate effectively about DCIS.

2 Conclusions

This thesis provides insight into the communication challenges of DCIS, and more widely, the communication challenges associated with non-invasive cancers and situations of uncertainty such as the uncertainty related to the medical evidence and the uncertainty related to the provisional nature of diagnostic and prognostic tests.

Furthermore, this thesis provides a greater understanding of the experiences of women diagnosed with DCIS and develops a practical tool, the DCIS communication Aid (CA), to be used by clinicians during their consultations with women with DCIS. This thesis also provides the first stage of development of recommendations, the *Key Communication Elements (DCIS)*, based on the best available evidence to assist clinicians to effectively communicate with women diagnosed with DCIS.

Further development and implementation of the *Key Communication Elements (DCIS)*, further evaluation and dissemination of the CA into routine clinical practice, and incorporation of the *Key Communication Elements (DCIS)* and CA into communication skills training programs has the potential to improve doctor-patient communication about DCIS and increase the well-being and health outcomes of women with DCIS.

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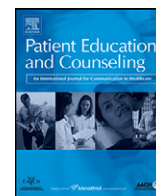
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Appendices

Appendices Chapter 2

Appendix 2.1

De Morgan S, Redman S, D'Este C, Rogers K. Knowledge, satisfaction with information, decisional conflict and psychological morbidity amongst women diagnosed with ductal carcinoma in situ (DCIS). Patient Educ Counsel 2011;84:62-68.



Patient Perception, Preference and Participation

Knowledge, satisfaction with information, decisional conflict and psychological morbidity amongst women diagnosed with ductal carcinoma in situ (DCIS)[☆]Simone De Morgan^{a,*}, Sally Redman^b, Catherine D'Este^c, Kris Rogers^b^a Faculty of Behavioural Science in Relation to Medicine, University of Newcastle, Newcastle, Australia^b The Sax Institute, Sydney, Australia^c Centre for Clinical Epidemiology and Biostatistics School of Medicine and Public Health, University of Newcastle, Newcastle, Australia

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ABSTRACT

Objective: To assess knowledge, satisfaction with information, decisional conflict and psychological morbidity amongst women diagnosed with ductal carcinoma in situ (DCIS) and to explore the factors associated with less knowledge and greater confusion about DCIS.

Methods: A cross-sectional survey of women diagnosed with DCIS in Australia ($N = 144$).

Results: This study found misunderstanding and confusion amongst women diagnosed with DCIS and a desire for more information about their breast disease. Approximately half of participants worried about their breast disease metastasizing; approximately half expressed high decisional conflict; 12% were anxious and 2% were depressed. Logistic regression analysis demonstrated that worry about dying from the breast disease was significantly associated with not knowing that DCIS could not metastasize (OR 3.9; 95% CI 1.03–14.25); and confusion about whether DCIS could metastasize was significantly associated with dissatisfaction with information (OR 12.5; 95% CI 3.8–40.2).

Conclusion: Good communication about how DCIS differs from invasive breast cancer is essential to alleviating the confusion and worry amongst women with DCIS.

Practice implications: Recommendations about how best to communicate a diagnosis of DCIS, including the uncertainties, are needed to guide health professionals to promote better understanding about DCIS and increase the well-being of women with DCIS.

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1. Introduction

The incidence of ductal carcinoma in situ has increased with the commencement and escalation of screening mammography worldwide [1,2]. Unlike invasive breast cancer, DCIS cannot metastasize and a woman cannot die from DCIS unless it develops into invasive breast cancer [3]. Some but not all DCIS will develop into invasive breast cancer if left untreated. The best estimates are that 14–53% of untreated DCIS may progress to invasive breast cancer over a period of 10 years or more [4]. However, the natural history of DCIS is not well understood and it is currently not possible to accurately predict which women with DCIS will go on to develop invasive breast cancer [5,6]. This uncertainty complicates treatment decision making for patients and doctors [4,6,7].

Studies suggest that women with DCIS may not fully understand their diagnosis and its implications [7–12]. A lack of

knowledge about DCIS may result in an unnecessary psychological burden on women and indeed women with DCIS have been found to experience similar levels of psychological distress to women with invasive breast cancer [10,11]. Research about the information needs of women with DCIS highlights that many are dissatisfied with the information about their diagnosis [7,8,13–15]. Any confusion about DCIS and its implications is likely to make decisions about treatment more difficult for women.

Previous research, using qualitative methodology, has explored women's understanding of their DCIS diagnosis, and their satisfaction with information and treatment decision making [7,11,13–15]. Quantitative studies have assessed knowledge, risk perceptions, psychological morbidity, and quality of life amongst women with DCIS. Women's satisfaction with information has been assessed in two quantitative studies in terms of satisfaction with 'information from doctors' and 'information related to future health problems'; [8] and satisfaction with 'information about the disease', 'information about surgery', and 'information about radiotherapy' [16], but there has been no research on satisfaction with information about the various aspects of the diagnosis and treatment in women with DCIS. While cancer-specific worry has been assessed in two quantitative studies in terms of the level of 'worry about getting breast cancer'; [8] and the level of 'intrusive or

[☆] I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

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avoidant thoughts' in response to the diagnosis [8,12] no previous studies have investigated the frequency of worry about the various breast cancer-related events specific to DCIS. In addition, there is a lack of information about confusion relating to the diagnosis; or decisional conflict in women with DCIS.

We undertook a study to assess knowledge, satisfaction with information, decisional conflict and psychological morbidity amongst women diagnosed with DCIS. We were particularly interested in women who did not know that DCIS cannot metastasize or were confused about whether DCIS can metastasize as this has emerged as a central concern in previous qualitative work [7]. We therefore tested the hypotheses that (a) not knowing that DCIS cannot metastasize and (b) being confused about whether DCIS can metastasize, is associated with not receiving or not being satisfied with information about this aspect of the diagnosis; worry about dying from the breast disease or other breast cancer-related events; increased anxiety, depression, or decisional conflict; choosing a mastectomy; and a range of demographic factors (older age, residing in rural or remote area, lower education levels, not being employed, or having a non-English speaking background). We also collected qualitative data to improve understanding of the meaning of the quantitative results.

2. Methods

2.1. Study population

Women who were eligible to participate in the study were diagnosed with ductal carcinoma in situ (DCIS) in NSW, Australia, and were notified to the NSW Central Cancer Registry (cancer registry) over a 1 year period. Notification of cancer to the cancer registry is legally required of all pathology laboratories, hospitals and radiotherapy facilities in NSW. Women were excluded if they had a previous or simultaneous diagnosis of invasive breast cancer, or micro-invasive disease which the cancer registry codes as invasive breast cancer. In addition, women were excluded if they were deemed by their doctor to be too ill or unable to speak English adequately for the self-completed survey. Women were recruited to the study 6–12 months after their diagnosis.

2.2. Sampling and participation

Confirmation of the woman's eligibility for the study was sought from doctors who notified women to the cancer registry. Of the 290 women who were identified by the cancer registry, 234 were deemed eligible by their doctor to participate in the study. Eligible women were informed about the study and asked for their consent to having their contact details forwarded from the cancer registry to the study investigators. Consenting women ($n = 159$) were sent an information package and the survey. Non-responding clinicians and women were followed-up by a letter and two telephone calls. The number of returned completed surveys was 144. The overall response rate was 62%. There were no significant differences between participants and eligible non-participants according to age, area of residence, or country of birth. Ethics approval to conduct the study was granted by the NSW Cancer Council Ethics Committee.

2.3. Measures

2.3.1. Measures developed by the authors

The authors developed specific items about knowledge, confusion, satisfaction with information, worry about the DCIS diagnosis, and psycho-social support from the authors' previous study with women with DCIS [7] and an exhaustive literature review. The developed items were reviewed by a multidisciplinary

team that included surgeons, a radiation oncologist, a psychiatrist, a breast nurse, senior academic health researchers, and seven women diagnosed with DCIS including one woman who was actively involved in breast cancer support networks. The individual items were not intended to be combined into summary scores or scales. The kappa statistic was used to assess the test–retest reliability of the survey with 34 participants (24% of the sample) who were amongst the first 40 participants to return the initial survey. Seventy percent of the developed items scored above 0.50 in Kappa analysis [17].

Knowledge items were developed to assess whether women comprehended the nature of their diagnosis. Twelve knowledge items were included with response options: *true*, *false* and *don't know*; one of the items assessed knowledge about whether DCIS could metastasize and was selected a priori for inclusion in the logistic regression analyses. Confusion items were developed to assess the level and content of women's 'bewilderment' about aspects of their diagnosis. Confusion is distinct from knowledge and has been described as one of the dimensions of emotional distress [18,19]. Seven confusion items were included with response options: *very confused*, *a little confused* and *did not feel confused*; one of the items assessed confusion about whether DCIS could metastasize and was selected a priori for inclusion in the logistic regression analyses. Cancer-specific worry has been shown to be distinct from risk perception [20,21] and anxiety and depression [22,23]. Worry items were developed to assess the frequency of worry about breast cancer-related events specific to the DCIS diagnosis. Four worry items were included with response options: *rarely or never*, *sometimes or occasionally*, *often*, and *most of the time*. Information items were developed to assess participants' satisfaction with information. Eleven information items were included with response options: *I would have liked more information*, *I received as much information as I needed*, *I received too much information*, *I didn't want any information* and *I would have liked information*. Three psycho-social support items were developed to assess whether participants had the opportunity to consult with a counsellor, breast nurse, psychologist or psychiatrist and included *yes* and *no* response options. Open questions in most sections of the survey enabled participants to make additional comments.

2.3.2. Decisional conflict

Decisional conflict was measured using the Decisional Conflict Scale (DCS) [24]. The DCS is a 16 item Likert scale that has demonstrated validity and reliability in a variety of population groups. The scale has five subscales: certainty; informed; values; social support; and perceived effective decision. The overall scores and subscores range from 0 (no decisional conflict) to 100 (extremely high decisional conflict). Scores exceeding 37.5 are associated with delayed decision making and decision reject [25].

2.3.3. Anxiety and depression

Anxiety and depression were assessed using the 14 item Hospitalized Anxiety and Depression Scale (HADS), with scores of 11 or greater on the HADS anxiety and depression subscales considered indicative of substantial anxiety or depression, respectively, based on the validation of this measure [26]; and scores of 8 or greater (scores that included cases and doubtful cases) as they have been shown to improve the sensitivity of the HADS scale, particularly the HADS Anxiety Scale [27,28] and have identified patients with prolonged psychological distress [29].

2.3.4. Participant characteristics

Date of diagnosis; age; residence; first language; Aboriginal or Torres Strait Islander origin; education; relationship status; employment status; usual occupation; whether any close family

members or close friends were diagnosed with breast cancer; and type of treatment were included in the survey.

2.4. Data analysis

Numbers and percentages are presented for socio-demographic and treatment characteristics of the sample and for the responses to items in the survey. We selected knowledge about whether DCIS could metastasize and confusion about whether DCIS could metastasize as the two main outcomes of interest because understanding that DCIS cells lack the capacity to metastasize, and therefore cannot cause death, is the central issue in understanding how DCIS differs from invasive breast cancer, and our qualitative work highlighted that many women were confused about this aspect. Factors associated with the two main outcomes of interest were initially investigated using Chi-square analyses followed by logistic regression analysis to adjust for potential confounders. Variables were included in the logistic regression analysis if they had a *p* value of 0.25 or less on univariate analyses and backward stepwise regression used to exclude variables with a *p* values of >0.1 on Wald tests. The goodness-of-fit of the model was tested using the Hosmer–Lemeshow tests. Factors of interest were (1) *information*: satisfaction with information about DCIS metastasizing (yes vs no); and receiving information about DCIS metastasizing (yes vs no); (2) *worry relating to the diagnosis*: worry about DCIS metastasizing (yes vs no); worry about dying from your breast disease (yes vs no); worry about developing breast cancer in the same breast or chest wall (yes vs no); worry about developing breast cancer in the opposite breast (yes vs no); (3) *anxiety and depression*: anxiety by HADS (definite case ≥ 11 vs non-case/doubtful case < 11, definite case/doubtful case ≥ 8 vs non-case < 8); no tests of association were performed using depression by HADS as the number of cases for depression was less than 10%; (4) *decisional conflict*: Decisional Conflict Scale (high decisional conflict >37.5 vs low decisional conflict ≤ 37.5); (5) *participant characteristics*: age (<60 years vs ≥ 60 years); residence (urban vs rural/remote); first language spoken (English vs non-English); education (tertiary vs non-tertiary); employment (employed vs not employed); lumpectomy only (yes vs no), mastectomy only (yes vs no); lumpectomy and mastectomy (yes vs no); no surgery after biopsy (yes vs no); radiotherapy (yes vs no). SAS Statistical software (Version 9.13) was used for all statistical analysis and a 5% significance level was used.

The qualitative data from open questions were coded into themes and sub-themes using thematic analysis and have been reported briefly in Section 3 [30].

3. Results

3.1. Sample characteristics

The characteristics of the sample are outlined in Table 1. The mean age of participants was 56 years old (SD 10.34). Most participants lived in a city, were currently in a relationship, and spoke English as their first language. Approximately half of the participants had a tertiary education and were currently employed.

3.2. Description of the type of breast disease amongst participants

Most participants (73%) described their disease as an early stage breast cancer. However, most participants (72%) also described their breast disease as a breast cancer contained in the milk ducts of the breasts and 59% described their breast disease as a non-invasive breast cancer. Forty-four percent of participants described their breast disease as a pre-cancer, and 26% thought they had a pre-cancer and an early stage breast cancer.

Table 1

Characteristics of study sample (*N* = 144).

	<i>n</i> (%)
Age	
Range	27–79 years
<60 years	78 (57%)
≥ 60 years	60 (43%)
Mean	56.41 years
Standard deviation	10.34
Area of residence	
Major city	101 (70%)
Rural/remote	40 (28%)
Educational level	
Non-tertiary	69 (48%)
Tertiary	73 (51%)
Employment	
Not employed (home duties/retired/unable to work)	73 (51%)
Employed (employed P/T or F/T/self-employed)	70 (49%)
Relationship status	
In a relationship (married/de facto)	109 (76%)
Not in a relationship (divorced or separated/widowed/single)	34 (24%)
English as first language	131 (91%)
Aboriginal or Torres Strait Islander	1 (1%)
Family member/close friend with breast cancer	79 (55%)
Treatment	
Lumpectomy only	75 (52%)
Mastectomy only	33 (23%)
Lumpectomy and mastectomy	18 (13%)
No additional surgery (after biopsy)	18 (13%)
Radiotherapy	56 (39%)
Axillary lymph node removal	25 (17%)
Hormonal therapy, e.g. Tamoxifen	18 (13%)

Not all categories sum to 100% because of missing data. Missing data for age at diagnosis: *n* = 8 (6%). Missing data in other categories ranged from 0 to 3 (0–2%).

3.3. Knowledge about DCIS

Of the participants surveyed, 60% thought that DCIS could metastasize, 27% did not know, and only 12% knew that DCIS could not metastasize. Only 19% of participants were aware of the natural history of DCIS, that is, that not *all* women with DCIS would develop invasive breast cancer if left untreated. Most participants (88%) understood that the aim of treating DCIS was to remove the DCIS and prevent it from developing into the type of breast cancer that can spread to other parts of the body.

3.4. Confusion about the diagnosis and treatment of DCIS

Table 2 outlines the confusion amongst participants about aspects of their diagnosis and treatment. Forty-three percent of participants were confused about whether their breast disease could metastasize and about the chances of their breast disease metastasizing or dying from the breast disease after treatment. Participants were also confused about their type of breast disease, and their ipsilateral and contralateral breast cancer risk. Participants were less confused about why they needed the type of treatment they had compared to other aspects of their diagnosis.

Participants reported that they felt confused about whether they had ‘cancer’ or not. Participants’ confusion was compounded by the conflicting descriptions about DCIS amongst health professionals, and by the same health professional, and in information available on the internet.

“My GP explained to me that I did not have cancer. My specialist explained that I did have early cancer. I was very worried about the two different answers I received.”

Table 2

Confusion amongst participants about aspects of their diagnosis and treatment.

	Confused, n (%)
<i>Diagnosis</i>	
(i) The type of breast disease you had	46 (32%)
(ii) Whether or not you have the type of breast cancer that can spread to other parts of your body	59 (43%)
(iii) The chances of your breast disease spreading to other parts of your body or dying from your breast disease if you did not have treatment	38 (27%)
(iv) The chances of developing breast cancer in the opposite breast	60 (44%)
<i>Treatment</i>	
(i) Why you needed the type of treatment you had	20 (14%)
(ii) The chance of developing breast cancer in the same breast or in the chest wall (if your breast has been removed)	65 (47%)
(iii) The chances of your breast disease spreading to other parts of your body or dying from your breast disease after treatment	59 (42%)

Missing data for each item ranged from 2 to 7 (1–5%).

Participants also reported that they had not heard about DCIS prior to their diagnosis and that this made the diagnosis more shocking and difficult to understand.

3.5. Satisfaction with information

Table 3 outlines the number of participants who were not satisfied with information about their diagnosis and treatment due to inadequate information.

Participants also suggested that information about the diagnosis be repeated in follow-up consultations, and that more written information about their disease would be helpful.

3.6. Treatment decision making

Participants were asked to complete the Decisional Conflict Scale (DCS) if they felt they had been involved in treatment decision making. Most participants [$n = 114$ (79%)] completed the Decisional Conflict Scale. Overall, 47% of respondents expressed high decisional conflict (score >37.5). The total mean DCS score for

participants was 20.5 (SD = 15.6), with 51% expressing high decisional conflict on the uncertainty subscales (mean = 21.2, SD = 18.2), 51% on the informed subscale (mean = 23.9, SD = 22.0), 45% on the values clarity subscale (mean = 21.7, SD = 17.4), 52% on the support subscale (mean = 21.7, SD = 17.5), and 42% on the effective decision subscale (mean = 18.2, SD = 14.3).

3.7. DCIS-specific worry

Table 4 outlines the worry amongst participants relating to the DCIS diagnosis. Approximately half of participants worried about their breast disease metastasizing, 43% worried about dying from their disease, 66% worried about developing breast cancer in the same breast or chest wall (if the breast was removed) after treatment, and 75% worried about developing breast cancer in the opposite breast.

3.8. Anxiety and depression by the HADS

The mean HADS Composite Scale score was 7.89, the mean HADS Anxiety Subscale score was 5.52, and the mean HADS

Table 3

Satisfaction with information about the diagnosis and treatment of DCIS.

	Not satisfied (inadequate information), n (%)
<i>Diagnosis</i>	
(i) The type of breast disease you had	48 (34%)
(ii) Whether or not you have the type of breast cancer that can spread to other parts of your body	74 (54%)
(iii) The chances of your breast disease spreading to other parts of your body or dying from your breast disease if you did or did not have treatment	51 (36%)
(iv) The risk of your daughter(s) developing breast cancer	56 (44%)
<i>Treatment</i>	
(i) All of the possible treatments for your breast disease	30 (22%)
(ii) All the possible side effects of treatment(s) for your breast disease	49 (36%)
(iii) Breast reconstruction	28 (21%)
(iv) The impact of your treatment(s) on your sexuality	34 (26%)
(v) The chances that the recommended treatment(s) would work	30 (22%)
(vi) The chances of developing breast cancer in your breast or chest wall (if your breast was removed) after treatment	61 (44%)
(vii) How often you need check-ups	28 (20%)

Missing data for sexuality item: $n = 12$ (8%); breast reconstruction item: $n = 10$ (7%); and daughter developing breast cancer: $n = 18$ (13%). Missing data for other information items ranged from 0 to 7 (0–5%).

Table 4

Worry amongst participants relating to their diagnosis.

Worry relating to the diagnosis	Most of the time/often, n (%)	Sometimes or occasionally, n (%)	Rarely or never, n (%)
(i) Your breast disease spreading to other parts of your body	20 (14%)	56 (39%)	67 (47%)
(ii) Dying from your breast disease	13 (9%)	49 (34%)	81 (57%)
(iii) Developing breast cancer in the same breast or in the chest wall (if your breast has been removed)	20 (14%)	74 (52%)	48 (34%)
(iv) Developing breast cancer in the opposite breast	27 (19%)	80 (56%)	35 (25%)

Missing data in each category ranged from 0 to 2 (0–1.4%).

Table 5Factors associated with poor knowledge, that is, not knowing that DCIS cannot metastasize (*logistic regression analyses*).

Parameter	Level	Odds ratio	Confidence interval (95%)	LR test statistic (df)	p-Value
(i) Worry about dying from your breast disease	Never worry Worry	Reference 3.9	1.03–14.25	4.03 (1)	0.045

Hosmer–Lemeshow GOF test: $\chi^2=0.102$, $df=2$, $p=0.9501$ (no evidence that model does not have adequate fit). There were no significant associations found between not knowing that DCIS could not metastasize and other variables.

Table 6Factors associated with confusion about whether DCIS can metastasize (*logistic regression analyses*).

Parameter	Level	Odds ratio	Confidence interval (95%)	LR test statistic (df)	p-Value
(i) Satisfied with information about whether DCIS could metastasize	Satisfied	Reference			
	Not satisfied	12.5	3.8–40.2	10.2 (1)	0.001
(ii) Worry about developing breast cancer in the same breast or chest wall	Never worry	Reference			
	Worry	4.1	1.2–14.2	5.26 (1)	0.022
(iii) Worry about DCIS metastasizing	Never worry	Reference			
	Worry	3.3	0.92–12.1	3.53 (1)	0.066

Hosmer–Lemeshow GOF test: $\chi^2=6.43$, $df=5$, $p=0.2664$ (no evidence that model does not have adequate fit). There were no other significant associations found between confusion about whether DCIS could metastasize and other variables.

Depression Subscale score was 2.35. Of the participants surveyed, 12% were defined as anxious and 2% were defined as depressed by the HADS (score ≥ 11). In addition, 28% of participants had scores of ≥ 8 on the HADS Anxiety Subscale and 8% of participants had scores of ≥ 8 on the HADS Depression Subscale.

3.9. Psychological support

Sixty percent of participants had consulted with a psycho-social health professional; 40% with a breast nurse; 42% with a counsellor; and 8% with a psychologist or psychiatrist.

3.10. What factors are associated with poor knowledge about DCIS?

In the univariate analyses, worry relating to the DCIS diagnosis (dying from your breast disease, developing breast cancer in opposite breast) was significantly associated with not knowing that DCIS could not metastasize (responding *False* or *Don't Know* to Knowledge item *If left untreated, DCIS alone cannot spread to other parts of the body*). In the logistic regression analyses, worry about dying from your breast disease was significantly associated with not knowing that DCIS could not metastasize (OR 3.9; 95% CI 1.03–14.25) (see Table 5). Participants who did not know that DCIS could not metastasize had 4 times the odds of worrying about dying from their breast disease. There were no significant associations found between not knowing that DCIS could not metastasize and other variables in the univariate or logistic regression analyses.

3.11. What factors are associated with confusion about DCIS?

In the univariate analyses, living in a rural or remote location rather than a city; receiving information about whether DCIS could metastasize; dissatisfaction with information about whether DCIS could metastasize; worry relating to the DCIS diagnosis (DCIS metastasizing; dying from your breast disease; developing breast cancer in same breast; developing breast cancer in opposite breast); consulting with a breast nurse; and high decisional conflict >37.5 were significantly associated with confusion about whether DCIS could metastasize (responding *I feel a little or very confused* to Confusion item *Do you feel confused about whether or not you had the type of breast disease that could spread to other parts of your*

body?). In the logistic regression analyses, dissatisfaction with information about whether DCIS could metastasize was significantly associated with confusion about whether DCIS could metastasize (OR 12.5; 95% CI 3.8–40.2) (see Table 6). Participants who were not satisfied with the information they received about whether their breast disease could metastasize had 12.5 times the odds of being confused about whether their breast disease could metastasize (95% CI) compared to participants who were satisfied with the information. Worry about developing breast cancer in the same breast or chest wall (OR 4.1; 95% CI 1.2, 14.2) was also significantly associated with confusion about whether DCIS could metastasize; while worry about DCIS metastasizing was marginally non-significant (OR: 3.3; 95% CI 0.92–12.1). There were no significant associations found between confusion about whether DCIS could metastasize and other variables in the univariate or logistic regression analyses.

4. Discussion and conclusion

4.1. Discussion

This study found that many participants did not understand how DCIS differs from invasive breast cancer with only 12% of participants knowing that DCIS could not metastasize. Participants were also confused about their type of breast disease. The confusion was compounded by the different descriptions of DCIS they received from various health professionals, and even by the same health professional, such as 'early breast cancer', 'pre-cancer' and 'non-invasive breast cancer' and by the information available about DCIS on the internet. Studies with women with DCIS have found that women's description of their breast disease varies greatly [7,11,14,15]. Similarly, research with doctors has found that consistent terms were not used when speaking with patients about DCIS [31]. Further research is needed to examine why variation exists and to develop consensus guidelines for health professionals, based on women's perspectives, about how best to describe DCIS.

Health professionals may also need guidance about how best to communicate the uncertainty associated with the natural history of DCIS. The shift towards informed consent and shared decision making, means that doctors must effectively communicate

medically relevant knowledge including the risks and uncertainties [32–34]. In a recent qualitative study, most women wanted more honest information about DCIS including information about the uncertainties relating to DCIS [11]. However, currently there are no clear best practices for presenting uncertainty to patients [35]. The present study found that only 19% of participants knew that not *all* women with DCIS would develop invasive breast cancer if untreated. Research suggests that doctors fear that communicating uncertainty to patients may undermine patient trust [36], that patients will perceive them as inadequate or ineffective [37], and that it will increase patients' anxiety [38]. Perhaps doctors also fear that disclosing the uncertainty about the natural history of DCIS may affect patients' willingness to have treatment. The impact of communicating various types of uncertainty on patients has been shown to vary according to patients' cognitive, emotional and behavioural characteristics [37,39,40]. Further research is needed to assess patients' and doctors' responses to the uncertainty involved in DCIS, how to increase patients' tolerance to uncertainty and how to tailor communication about uncertainty to individual patients.

Meeting patients' information needs has been shown to increase understanding [41], and improve psychological adjustment and perceived quality of life [42–44]. The present study found that women with DCIS want more information about their type of breast disease, whether their breast disease can metastasize, the chances of dying from the breast disease if they did or did not have treatment, and the chances of local recurrence after treatment. The logistic regression analysis found that dissatisfaction with information about whether DCIS could metastasize was significantly associated with confusion about this aspect. Given the complexities involved in DCIS, good communication is essential to facilitate understanding of the information [45]. Simple strategies such as assessing patients' understanding during the consultation, repeating and summarizing key information, and actively encouraging questions can improve understanding of the information [43,46]. A limitation of this research is the small sample size, and low statistical power. Further research with a larger sample size will have greater power to detect factors associated with less knowledge and greater confusion about DCIS.

Adequate information is also needed to ensure participation in treatment decision making [47–49]. Qualitative studies suggest that women with DCIS experience difficulty in treatment decision making [7,11]. The present study found that more than half of participants experienced high decision conflict. High decisional conflict has been shown to result in delayed decision making and feeling emotionally distressed by the decision [50]. In the univariate analysis in the present study, high decisional conflict was significantly associated with confusion about whether DCIS could metastasize. Better communication about how DCIS differs from invasive breast cancer may reduce decisional conflict in women with DCIS. Decisional conflict may also be lowered by involving patients in treatment decision making [51] and with decision supporting interventions that inform patients about options, benefits, risks, and side effects and that clarify personal values of treatment outcomes [52].

Confusion and misunderstanding about DCIS may result in an unnecessary psychological burden for women. The level of psychological morbidity found in the present study was comparable with other studies with women with DCIS [12] and invasive breast cancer [53] measured by the HADS. The present study found no association between knowledge and confusion about whether DCIS could metastasize and anxiety by the HADS, comparable to the only other study that has measured psychological morbidity in women with DCIS using the HADS [12]. However, this study found that other aspects of knowledge such as overestimated risk perceptions of local recurrence were associated with increased

anxiety in women with DCIS [12]. Although knowledge about whether DCIS could metastasize was not found to be associated with anxiety in general in the present study, it was found to be significantly associated with cancer-specific worry. Cancer-specific worry has been shown to be distinct from anxiety and depression. Using DCIS-specific worry items developed by the authors, the present study found that a high proportion of participants worried about their breast disease metastasizing, dying from their breast disease, and local breast cancer recurrence after treatment; and that not knowing that DCIS could not metastasize was found to be significantly associated with worry about dying from the breast disease. Better communication about how DCIS differs from invasive breast cancer is essential to alleviating the cancer-specific worry in women with DCIS. Good communication is also needed to elicit and respond to the emotional concerns or 'cues' and cancer-specific worries of women and refer to support services when needed [54,55]. Further research is needed to identify the subtypes of women with DCIS who may be in most need of support [21,56–60]. In addition, a longitudinal design is needed to explore whether anxiety and depression and cancer-specific worry improve over time. The impact of worry on mood or functioning may also be explored in future studies.

Lack of understanding about DCIS may be even more pronounced in women from non-English speaking backgrounds. For example, Latina US women have been found to have poorer knowledge about DCIS and more psychological distress than White women [15] and Chinese Canadian women with DCIS have also been found to have poorer knowledge about DCIS [61]. Further research is needed to assess the understanding and impact of a DCIS diagnosis amongst women from non-English speaking backgrounds.

Although this study benefits from the inclusion of survey items developed specifically for women with DCIS, development of knowledge, confusion and DCIS-specific worry scales with further validation would be useful given the paucity of rigorously tested psychometric instruments specific to the DCIS diagnosis.

4.2. Conclusion

This study found misunderstanding and confusion amongst women diagnosed with DCIS. Women's confusion was compounded by inadequate information about DCIS and conflicting descriptions about DCIS from health professionals. The study also found that women who had poor knowledge about DCIS were more likely to worry about dying from DCIS, resulting in an unnecessary psychological burden for women with DCIS.

4.3. Practice implications

Good communication is essential to address the two most challenging communication issues relating to DCIS. Firstly, communicating to women that DCIS cells lack the biological capacity to metastasize. Secondly, communicating to women the uncertainty relating to the natural history of DCIS. The communication challenges highlighted in this study are not only relevant to DCIS but to other non-invasive cancers that are increasingly being detected in this age of screening. Further research is needed to examine the difficulties health professionals experience in communicating about DCIS. Recommendations about how best to communicate a diagnosis of DCIS, derived from women's perspectives, are needed to guide health professionals to promote better understanding about DCIS and increase the well-being of women with DCIS.

Conflict of interest statement

None.

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Appendix 2.2

Dear Dr _____

About your diagnosis

The NSW Central Cancer Registry is assisting researchers by identifying women with ductal carcinoma in situ (DCIS) who may be eligible for the above study.

May the Registry contact patients of yours with a recent diagnosis of DCIS? We would be asking your patients if the research team could use their contact details to write to them. The research team would inform your patients about the study and seek their consent.

Consenting women will be asked to initially complete a survey about their experience of being diagnosed with DCIS. At the end of the survey, the investigators will invite women who participated in the survey to take part in a telephone interview. As part of the second stage of the study subjects will be asked for limited access to their medical records. The study is described in more detail in the enclosed leaflet. While it is not necessary for you to do so, we would be happy for you to speak to your patients about this study.

I enclose forms listing patients of yours with DCIS who have been notified to the Registry. I would be grateful if you would indicate whether your patients may be approached and fax completed forms to the Registry on (02) 9368 0843. The death index supplied by the Registrar General will be routinely checked before sending letters to patients (this index is updated fortnightly).

If patients do not respond within 14 days of the letter from us, a Registry staff member will phone them to obtain their verbal consent or refusal. All patients who give verbal consent will be asked to complete and return a written consent form before participating in the study. Information about patients will not be used for this research without their consent.

Approval for this study has been granted by the NSW Cancer Council Ethics Committee. All information obtained will be kept strictly confidential. You will not be identified in this study or in any reports or published papers arising from this study.

If you have any queries about this request, or would prefer to call us with your response, please telephone **Ms Lesley Porter on (02) 9334 1803**.

If we do not hear from you within 10 working days, we will contact you by phone.
Thank you for your help.

Yours sincerely

Elizabeth Tracey
Manager, Cancer Registers
Date

**REQUEST FOR PERMISSION TO APPROACH A PATIENT
WITH A DIAGNOSIS OF DUCTAL CARCINOMA IN SITU (DCIS)**



Dr

Address

STUDY ELIGIBILITY CRITERIA

- Notified to the Cancer Registry
between 1 January 2001 and 30 June 2001
- Never been diagnosed with invasive breast cancer
- Resident in NSW
- Well enough to take part
- No assistance required to complete a written survey and no
interpreter required to complete a telephone interview

Patient name

Patient DOB

The NSW Central Cancer Registry may approach the above patient in writing to seek their agreement to give their contact details to the researchers conducting the *About your diagnosis* study.

No Yes

I have spoken to this patient about the study.

I referred this patient. Please contact: →

Doctor name

The above patient should NOT be approached for the following reason(s):
(tick as many as apply):

Diagnosis is not ductal carcinoma in situ (DCIS)

Has been diagnosed with invasive breast cancer

Not a NSW resident

Not able to answer a written survey without assistance or be interviewed in English

Too ill

Deceased

Other (please specify)

Please use the reply-paid envelope to return completed forms to:

NSW Cancer Registry
Locked Mail Bag 1
Kings Cross NSW 1340
or **FAX to: (02) 9368 0843**

THANK YOU FOR YOUR CO-OPERATION



Information for clinicians

What is the purpose of the study?

To improve our understanding of women's experience of being diagnosed with ductal carcinoma in situ (DCIS) and the pathways to diagnosis of DCIS, including attendance at BreastScreen.

We aim to use the information obtained from this study to design strategies to increase women's understanding of DCIS and guide development of appropriate psychosocial support programs.

The National Breast Cancer Centre is conducting and funding the study.

How will women be selected to participate?

Women diagnosed with DCIS and notified to the NSW Central Cancer Registry between 1 January 2001 and 30 June 2001 will be asked to participate with the cooperation of the Cancer Registry.

How will the information be collected?

Briefly we propose the following:

Cancer Registry staff will identify women with DCIS from 1 January 2001 to 30 June 2001. For each woman, a letter will be sent from the Registry to the notifying practitioner requesting his or her written permission to approach the woman about the study. Once this permission is received, the Registry will write to the woman requesting permission to pass on her contact details to the researchers. Practitioners will not be obliged to seek their patients' consent themselves, but we would welcome them doing this should they choose to. No woman will be approached to participate in this study without the clinician mainly responsible for her care agreeing that we may contact her.

Who is eligible?

Women who meet the following criteria are eligible for the study:

- Notified to the Cancer Registry between 1 January 2001 and 30 June 2001
- Never been diagnosed with invasive breast cancer
- Resident in NSW
- Well enough to take part
- No assistance required to complete a written survey and no interpreter required to complete a telephone interview

What does the study involve?

Part A of the study:

A self-completed survey sent to women and designed to take 30 to 40 minutes to complete. Women will be asked about their understanding of their diagnosis, their experience of being diagnosed with DCIS, how they feel emotionally and their mammographic history in the last five years.

Part B of the study:

Women who participated in Part A of the study will be invited to participate in Part B of the study. Part B involves a telephone interview about women's recent diagnosis of DCIS. Women will be asked questions about how they were diagnosed; their access to and use of services and their risk factors such as age at menarche and menopause, childbearing, and family history of breast cancer and history of benign breast disease.

All women participating in Part B of the study will be asked for written permission to confirm mammography in BreastScreen in the five years before diagnosis. Women will also be asked for written permission to obtain pathology reports of their DCIS for standardised data review.

Participation in the study program is entirely voluntary. Women may choose to participate in Part A of the study only. Women may withdraw at any time after they have agreed to participate in any part of the study.

Need more information?

If you have any queries about this study, or would prefer to call us with your response, please telephone

Ms Lesley Porter on (02) 9334 1803

This study has been approved by the NSW Cancer Council Ethics Committee.

The Research Team

National Breast Cancer Centre

Professor Sally Redman

Dr Anne Kricker

Ms Simone De Morgan

Ms Lesley Porter

National Breast Cancer Centre

Street Address

153 Dowling Street

Woolloomooloo

Postal Address

About your diagnosis

Locked Mail Bag 1

Kings Cross NSW 1340

Appendix 2.3

Dear

About your diagnosis

I am writing to tell you about research being done about women's experience of being diagnosed with ductal carcinoma in situ (DCIS) and to ask if you would consider taking part. Your doctor has been informed about this study and has given approval for us to write to you. The study is being conducted by the National Breast Cancer Centre.

The NSW Central Cancer Registry has been notified that you were recently diagnosed with DCIS. We receive information about everyone diagnosed with DCIS in NSW and ACT under the authority of the NSW Public Health Act. I have enclosed a leaflet describing the Cancer Registry and how it operates.

An information leaflet (enclosed) describes the research and what you would be asked to do if you took part. The NSW Cancer Council's Ethics Committee has approved this study.

Would you be willing for the research team to use your name and address, as recorded on our Registry, to write to you about participating in the study? You will be free to decide whether you wish to participate when you receive the letter from the research team.

Your participation in the study would greatly help to improve the care and treatment of women diagnosed with DCIS in the future. I would be grateful if you would sign and complete the attached form to let me know your decision as soon as you can.

If you would like to speak to someone about this request, you can call
Ms Lesley Porter on Freecall 1800 500 105

If we have not heard from you in a couple of weeks, we will phone you to find out what you would like to do.

Yours sincerely

Elizabeth Tracey
Manager, Cancer Registers
Date



About your diagnosis

RESPONSE FORM

Full Name:

Please read this section very carefully, then tick one box to indicate YES or NO and sign and date the form.

☐

YES

I am willing for the researchers conducting the study *About your diagnosis* to use my contact details in the Cancer Registry to write to me. I will be free to decide whether I wish to participate at that time.

I understand that my details will be treated in the strictest confidence and will be used for medical research purposes only. No identifying information will be given to anyone outside the research team.

☐

NO

I am not willing for the researchers conducting the study *About your diagnosis* to use my contact details in the Cancer Registry to write to me or contact me in the future.

Your signature

Date

Please use the reply paid envelope to return completed form to
NSW Cancer Registry Locked Mail Bag 1
Kings Cross NSW 1340

THANK YOU FOR YOUR CO-OPERATION

Appendix 2.4

Dear

About your diagnosis survey

I am writing to ask if you would be willing to help with the survey *About your diagnosis*. The survey is being carried out by the National Breast Cancer Centre. The survey aims to find out what you were told about your diagnosis, how satisfied you are with the information you received, how you made a decision about treatment, and how you are feeling now. This is a very important survey that will help us improve the care of women diagnosed with DCIS in the future. Your opinions and experiences are important to us and we hope that you will be able to take part in the survey.

With your agreement the NSW Central Cancer Registry has given us your name and address so that we could write to you.

If you wish to take part, please complete the survey (enclosed) and return it to us in the reply paid envelope (enclosed). At the end of the survey, you will be invited to take part in a telephone interview. You may choose to complete the survey and not take part in the telephone interview. This is entirely up to you to decide. For more information about the survey and the telephone interview please read the information leaflet (enclosed).

All information collected from you is **totally confidential**. The information published from the research will not contain your name or identify you in any way. Your surgeon has been informed about this survey and has given approval for us to write to you. However, your surgeon or any other doctor who has treated you will not know about any issues or problems you discuss with us and we will not tell them whether you choose to participate in the survey or not.

If you would like to get more information about the survey, you can call Ms Lesley Porter or Ms Simone De Morgan on **Freecall 1800 500 105**

If we have not heard from you in a couple of weeks, we will telephone you to find out if you agree to take part in the survey and to answer any questions you may have.

Participation in the survey is entirely voluntary and you can choose to withdraw at any time. Whatever you decide, you can be assured that your choice will not change your medical treatment or care in any way.

In addition to completing this survey, you may feel that you would benefit by talking with someone else such as a counsellor about any feelings or concerns that you may have. You can contact **The Cancer Helpline** on **13 20 11** (Freecall).

The people who run this service are experienced in talking to women diagnosed with DCIS and breast cancer. They can offer you information and support. They can also give you information about health professionals such as counsellors, psychologists or psychiatrists who are experienced in talking with women in your situation.

Alternatively, you may wish to talk about your feelings or any concerns you may have with your general practitioner or you may ask your general practitioner to refer you to an appropriate health professional. It is common for women to feel strong feelings and have concerns in your situation. Help is available if you need it. Don't put up with any feelings that you feel overwhelmed by.

This study has been approved by the NSW Cancer Council Ethics Committee. If you have any concerns about its conduct you can contact the Secretary of the Committee, Ms Angela Aston, on (02) 9334 1889.

I do hope that you will be able to help us by finding the time to complete the survey (enclosed) and returning it to us in the reply paid envelope. Your views are very important to the success of this study and will help other women diagnosed with DCIS in the future.

Yours sincerely

Dr Anne Kricker
Senior Epidemiologist and
Study Director
National Breast Cancer Centre

Professor Sally Redman
Chief Executive Officer
National Breast Cancer Centre

Telephone numbers

- ◆ Information about the study: Ms Lesley Porter or Ms Simone De Morgan on Freecall 1800 500 105
- ◆ Concerns about the conduct of the study: Ms Angela Ashton on (02) 9334 1889
- ◆ For additional support: Cancer Helpline on Freecall 13 11 20

Appendix 2.5

About your diagnosis Information about the study



Why is the study being done?

To improve our understanding of the experience of being diagnosed with ductal carcinoma in situ (DCIS). The study aims to find out how you understand the type of breast disease you had, how satisfied you are with the information you received, how you made a decision about treatment, how you are feeling now and your history of mammograms.

The study is being conducted by the National Breast Cancer Centre. This is a very important study that will help us improve the care of women diagnosed with DCIS in the future. Your opinions and experiences are important to us and we hope that you will be able to participate in the study.

Who will be in the study?

We are inviting women with DCIS diagnosed between January and June 2001.

What will you be asked to do?

A survey:

In the first part of the study, a survey will be sent to you. The survey takes about 30 to 40 minutes to complete and will ask about:

- how you understand the type of breast disease you had
- how satisfied you are with the information you received
- how you made a decision about treatment
- how you are feeling now and
- how you were diagnosed

A small number of women who complete the survey will be asked (two weeks after completing the survey) if they are willing to complete the first two sections of the survey again. This should only take ten minutes to complete. This is a common research method to test whether a survey is reliable. We need to test whether the survey is reliable so that we are able to be certain that the results of the study truly reflect what women are experiencing after a diagnosis of DCIS.

A telephone interview:

At the end of the survey you will be invited to take part in a telephone interview. You may choose to complete the survey and not to take part in the telephone interview. This is entirely up to you to decide. Your information will still be very valuable to us.

You will be asked at the end of the survey about whether you wish to receive more information about the telephone interview. The telephone interview generally takes 30-45 minutes. If you agree to take part in the telephone interview we will call and make a time that is convenient for you, including evenings. We will also ask you for your written permission for us to seek access to records of past mammograms in BreastScreen, copies of mammograms and pathology reports.

Will the information be kept confidential?

Yes. All the information you provide will be kept strictly confidential. Only authorised study staff will have access to the data. Names will be removed from records and replaced with a number code as soon as possible after collection and before analysis. You will not be able to be identified, either directly or indirectly, when the results of the study are reported.

Your doctors will not know about any issues or problems that you discuss with us and we will not tell your doctor whether you choose to participate in the study or not.

Why should you help?

If we knew more about how women felt after a diagnosis of DCIS and how they understand the nature of their disease we could better care for women diagnosed with DCIS in the future.

What if you don't agree to take part?

Participation in this study is entirely voluntary. You may withdraw at any time after you have agreed to take part. You may also choose to complete the survey and not to take part in the telephone interview. This is entirely up to you. The treatment and the care given to you will not be affected in any way if you choose not to take part in the survey or the telephone interview or to later withdraw.

Need more information?

If you would like more information about the study please call **Ms Lesley Porter or Ms Simone De Morgan on Freecall 1800 500 105** (Please leave a message and she will return your call as soon as possible)

Concerns about the project?

This study has been approved by the NSW Cancer Council Ethics Committee. If you have any concern about its conduct you can contact the Secretary of the Committee, Ms Angela Aston, on (02) 9334 1900 or write to her at The NSW Cancer Council Ethics Committee, PO Box 572, Kings Cross NSW 1340.

I do hope that you will be able to help us. Your views are very important to the success of this study and will help other women diagnosed with DCIS in the future.

Appendix 2.6

ID number:_____

About your diagnosis survey

Please answer all questions in the survey (Part A to Part F)

This survey should take about 30 minutes to complete

**Thank you for completing this survey
Your views and experiences are important to us**

Part A

Understanding your diagnosis

Your breast disease was called DCIS or ductal carcinoma in situ.

Please look at the following statements. For each statement, tick ONE answer that indicates whether you think the statement is TRUE or FALSE or you DON'T KNOW.

1	True	False	Don't Know
A I had breast cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
B I had an early stage breast cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C I had a pre-cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
D I had a non-invasive breast cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
E I had breast cancer that was contained in the milkducts of my breast	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
F I had an advanced breast cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
G If left untreated, DCIS can develop into the type of breast cancer that can spread to other parts of the body	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
H If left untreated, DCIS alone cannot spread to other parts of the body	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I All women diagnosed with DCIS <u>if they are not treated</u> will develop the type of breast cancer that can spread to other parts of the body	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
J The aim of treating DCIS is to remove the DCIS and prevent it from developing into the type of breast cancer that can spread to other parts of the body	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
K Even after treatment, there is still a chance that DCIS or breast cancer may come back in the breast (or in the chest wall if your breast was removed)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
L I have a greater chance of developing breast cancer in the other breast than women who have not been diagnosed with DCIS	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

2 Are there any comments you would like to make about the above statements?
If so, please explain below:

The following questions are about whether you are confused about anything about your breast disease. For each question, there are THREE possible answers to choose from. For each question, tick ONE answer that is right for you. Please answer every question.

3	<i>Do you feel confused about:</i>	I DO NOT feel confused	I feel a LITTLE confused	I feel VERY confused
A	The type of breast disease you had	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
B	Whether or not you had the type of breast cancer that could spread to other parts of your body	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C	Why you needed the type of treatment you had	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
D	The chances of developing breast cancer in the same breast or in the chest wall (if your breast has been removed)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
E	The chances of developing breast cancer in the opposite breast	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
F	The chances of your breast disease spreading to other parts of your body or dying from your breast disease AFTER treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
G	The chances of your breast disease spreading to other parts of your body or dying from your breast disease if you DID NOT have treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

4 Is there anything else that you feel confused about? If so, could you please explain below:

Now, thinking about your concerns and worries about your diagnosis, please look at the following questions. For each question, there are FOUR possible answers to choose from. For each question, tick ONE answer that is right for you. Please answer every question.

5	<i>How often do you worry about:</i>	Rarely or never	Sometimes or occasionally	Often	Most of the time
A	Developing breast cancer in the same breast or in the chest wall (if your breast was removed)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
B	Developing breast cancer in the opposite breast	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C	Your breast disease spreading to other parts of your body	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
D	Dying from your breast disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

6 Is there anything else that you feel worried about in relation to your breast disease? If so, could you please explain below:

7 Did you have the opportunity to meet with any of following health professionals while you were in hospital or at any other time to discuss your diagnosis and treatment or your concerns? Please tick either YES or NO.

	Yes	No
A A breast nurse	<input type="radio"/>	<input type="radio"/>
B A counsellor	<input type="radio"/>	<input type="radio"/>
C A psychologist or psychiatrist	<input type="radio"/>	<input type="radio"/>

Part B

Satisfaction with information

Now, thinking about the information you received, both written information and information from your doctors or other members of your treatment team (Do not include information that you may have found yourself).

For each question, there are TWO categories:

1. NOT DISCUSSED OR DIDN'T RECEIVE ANY INFORMATION *and*

2. WAS DISCUSSED OR DID RECEIVE INFORMATION

For each question, tick ONE answer from ONE category that is right for you. Please answer every question.

	NOT DISCUSSED OR DIDN'T RECEIVE ANY INFORMATION		WAS DISCUSSED OR DID RECEIVE INFORMATION		
	I didn't want ANY information	I would have LIKED information	I would have liked MORE information	I received AS MUCH information as I needed	I received TOO MUCH information
1 Were you satisfied with the amount of information you received about the following:					
A The type of breast disease you had	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
B Whether or not you had the type of breast cancer that can spread to other parts of your body	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C All the possible treatments for your breast disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
D All the possible side effects of treatment(s) for your breast disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
E Breast reconstruction	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
F The impact of treatment(s) on your sexuality	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

		NOT DISCUSSED OR DIDN'T RECEIVE ANY INFORMATION		WAS DISCUSSED OR DID RECEIVE INFORMATION		
Were you satisfied with the amount of information you received about the following:		I DIDN'T want any information	I would have LIKED information	I would have liked MORE information	I received AS MUCH information as I needed	I received TOO MUCH information
G	The chances that the recommended treatment(s) would work	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
H	The chances of developing breast cancer in your breast or chest wall (if your breast was removed) AFTER treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I	The chances of your breast disease spreading to other parts of your body or dying from your breast disease if you DID <u>or</u> DID NOT have treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
J	The risk of your daughter(s) developing breast cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
K	How often you need check-ups	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

2 Is there anything else that you would like to say about the information you did or didn't receive?

Part C

About your treatment

Now, thinking about the treatment that you had for your breast disease and how you made a decision about your treatment. Please answer the following questions.

Which of the following treatment(s) did you have? Please tick ONE or MORE answers.

- ☐ I had a lumpectomy (only part of my breast was removed)
- ☐ I had a mastectomy (my whole breast was removed)
- ☐ The lymph glands under my arm were removed
- ☐ I had radiotherapy (X-Ray treatment to my breast)
- ☐ I had chemotherapy (Drug treatment)
- ☐ I had hormone drugs (eg Tamoxifen)
- ☐ I don't know
- ☐ I didn't have treatment

How did you decide about treatment? Please tick ONE answer below.

- ☐ The doctor made the decision using all that he or she knew about treatments
- ☐ The doctor made the decision but strongly considered my opinion
- ☐ The doctor and I made the decision together on an equal basis
- ☐ I made the decision but strongly considered the doctor's opinion
- ☐ I made the decision using all that I knew and learnt about the treatments

How satisfied are you with how much you were involved in deciding about your treatment? Please tick ONE answer that is right for you.

- ☐ I would have preferred to have been MORE involved in deciding about my treatment
- ☐ I am happy with the amount of involvement I had in deciding about my treatment
- ☐ I would have preferred to be LESS involved in deciding about my treatment

If you think you made the decision about your treatment (by yourself or with your doctor) please answer the questions on this page.



If you think your doctor made the decision about your treatment, please *do not* answer the questions on this page. Please go to Part D: about how you are feeling on the following page.



Now, thinking about the choice you made about your treatment for your breast disease please look at the following comments made by people when making decisions. Please show how strongly you agree or disagree with these statements by ticking ONE answer which best shows how you feel about the choice you made.

4		Strongly agree	Agree	Neither Agree Nor Disagree	Disagree	Strongly disagree
A	This decision was easy for me to make	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
B	I was sure what to do in this decision	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C	It was clear what choice was best for me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
D	I was aware of the options I had in this decision	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
E	I feel I knew the advantages of each option	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
F	I feel I knew the disadvantages of each option	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
G	I was clear about <u>how important</u> the advantages were to me in this decision	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
H	I was clear about <u>how important</u> the disadvantages were to me in this decision	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I	For the main options I considered, I was clear about which was more important to me (advantages and disadvantages)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
J	I made this choice without any pressure from others	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
K	I had the right amount of support from others in making this choice	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
L	I had enough advice about the options	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
M	I feel I have made an informed choice	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
N	My decision shows what is important to me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
O	I stuck to my decision	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
P	I am satisfied with my decision	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Part D: About how you are feeling

Now, thinking about how you have been feeling in the last week. Read each item and place a firm tick in the box opposite the reply which comes closest to how you have been feeling. Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought-out response. Tick only ONE answer in each section.

1A. I feel tense or 'wound up':

- ☐ Most of the time
- ☐ A lot of the time
- ☐ Time to time, occasionally
- ☐ Not at all

B. I still enjoy the things I used to enjoy:

- ☐ Definitely as much
- ☐ Not quite as much
- ☐ Only a little
- ☐ Hardly at all

C. I get a sort of frightened feeling as if something awful is about to happen:

- ☐ Very definitely and quite badly
- ☐ Yes, but not too badly
- ☐ A little, but it doesn't worry me
- ☐ Not at all

D. I can laugh and see the funny side of things:

- ☐ As much as I always could
- ☐ Not quite so much now
- ☐ Definitely not so much now
- ☐ Not at all

E. Worrying thoughts go through my mind:

- ☐ A great deal of the time
- ☐ A lot of the time
- ☐ From time to time but not too often
- ☐ Only occasionally

F. I feel cheerful:

- ☐ Not at all
- ☐ Not often
- ☐ Sometimes
- ☐ Most of the time

G. I can sit at ease and feel relaxed:

- ☐ Definitely
- ☐ Usually
- ☐ Not often
- ☐ Not at all

H. I feel as if I am slowed down:

- ☐ Nearly all the time
- ☐ Very often
- ☐ Sometimes
- ☐ Not at all

I. I get a sort of frightened feeling like 'butterflies' in the stomach:

- ☐ Not at all
- ☐ Occasionally
- ☐ Quite often
- ☐ Very often

J. I have lost interest in my appearance:

- ☐ Definitely
- ☐ I don't take so much care as I should
- ☐ I may not take quite as much care
- ☐ I take just as much care as ever

K. I feel restless as if I have to be on the move:

- ☐ Very much indeed
- ☐ Quite a lot
- ☐ Not very much
- ☐ Not at all

L. I look forward with enjoyment to things:

- ☐ As much as ever I did
- ☐ Rather less than I used to
- ☐ Definitely less than I used to
- ☐ Hardly at all

M. I get sudden feelings of panic:

- ☐ Very often indeed
- ☐ Quite often
- ☐ Not very often
- ☐ Not at all

N. I can enjoy a good book or radio or TV programme:

- ☐ Often
- ☐ Sometimes
- ☐ Not often
- ☐ Very seldom

Part E

Demographics

Finally, we'd like some information about you. This information is confidential.
For most questions please tick ONE answer. Please answer every question.

1A When were you diagnosed?

Month_____

Year_____

B How old are you?

- ☐ Less than 30 years
- ☐ 30 to 39 years
- ☐ 40 to 49 years
- ☐ 50 to 59 years
- ☐ 60 to 69 years
- ☐ More than 70 years

C What is your date of birth?

____/____/____

D What is the postcode of the suburb you live in?_____

E Is English your first language?

- ☐ Yes
- ☐ No

F Are you Aboriginal or Torres Strait Islander origin?

- ☐ No
- ☐ Yes

H Which of the following best describes your present relationship status?

- ☐ Married
- ☐ De facto or living with a partner
- ☐ Divorced or separated
- ☐ Widowed
- ☐ Single
- ☐ In a relationship but not living with partner

I Which of the following best describes your USUAL work situation?

- ☐ Home duties
- ☐ Retired
- ☐ Self-employed
- ☐ Employed: Full-time
- ☐ Employed: Part-time or casual
- ☐ Looking for work or unemployed
- ☐ Student
- ☐ Physically or mentally unable to work
- ☐ Other

J

What is your usual occupation? (if retired, looking for work or unable to work what was your most recent past occupation)

G Which of the following best describes your highest education level?

- ☐ Primary school only
- ☐ Some secondary school
- ☐ School Certificate /Year 10 / 4th form / Intermediate certificate
- ☐ HSC / Year 12 / 6th form / Leaving Certificate
- ☐ College (Diploma or Certificate) eg TAFE, business college
- ☐ University (Degree)

K Have any close members of your family, close friends or close members of your partner's (if relevant) family been diagnosed with breast cancer that you know of?

- ☐ No
- ☐ Yes

If yes, state your relationship with this person(s):

She is/was

*my*_____

She is/was

*my*_____

Part F
Your history of mammograms

1A Have you ever had a mammogram?

☐ Yes

☐ No

If No, Please go to Page 13

B How often, on average, did you have a mammogram before 1997?

☐ Every year

☐ Every three or four years

☐ Rarely

☐ Every 2 years

☐ One only



☐ None

C What was the first year that you had a mammogram? _____

2 For each year between 1997 and 1999 please tick Yes or No to indicate whether you had a mammogram in that year. If YES, please answer the questions for that year. If NO, please go on to next year.

	1997	1998	1999
A. Did you have a mammogram in that year?	<input type="radio"/> Yes <input type="radio"/> No <i>If No, please go on to next year</i> →	<input type="radio"/> Yes <input type="radio"/> No <i>If No, please go to next year</i> →	<input type="radio"/> Yes <input type="radio"/> No <i>If No, please go to next year</i> →
B. What state were you living in?	_____	_____	_____
C. What suburb were you living in?	_____	_____	_____
D. Where did you have your mammogram?	<input type="radio"/> BreastScreen van/clinic/hospital <input type="radio"/> Private clinic/radiologist <input type="radio"/> Other eg hospital not BreastScreen	<input type="radio"/> BreastScreen van/clinic/hospital <input type="radio"/> Private clinic/radiologist <input type="radio"/> Other eg hospital	<input type="radio"/> BreastScreen van/clinic/hospital <input type="radio"/> Private clinic/radiologist <input type="radio"/> Other eg hospital not BreastScreen
E. If you had a mammogram in that year, what town or suburb did you have the mammogram?	_____	_____	_____
F. Were you pregnant that year?	<input type="radio"/> Yes <input type="radio"/> No	<input type="radio"/> Yes <input type="radio"/> No	<input type="radio"/> Yes <input type="radio"/> No
G. Were you taking birth control pills that year?	<input type="radio"/> Yes <input type="radio"/> No	<input type="radio"/> Yes <input type="radio"/> No	<input type="radio"/> Yes <input type="radio"/> No
H. Were you taking hormone replacement therapy (HRT) that year?	<input type="radio"/> Yes <input type="radio"/> No	<input type="radio"/> Yes <input type="radio"/> No	<input type="radio"/> Yes <input type="radio"/> No

- 3 For each year between 2000 and 2002 please tick Yes or No to indicate whether you had a mammogram in that year. If YES, please answer the questions for that year. If NO, please go on to next year.

	2000	2001	2002
A. Did you have a mammogram in that year?	<input type="radio"/> Yes <input type="radio"/> No <i>If No, please go on to next year</i> 	<input type="radio"/> Yes <input type="radio"/> No <i>If No, please go on to next year</i> 	<input type="radio"/> Yes <input type="radio"/> No
B. What state were you living in?	_____	_____	_____
C. What suburb were you living in?	_____	_____	_____
D. Where did you have your mammogram?	<input type="radio"/> BreastScreen van/clinic/hospital <input type="radio"/> Private clinic/radiologist <input type="radio"/> Other eg hospital not BreastScreen	<input type="radio"/> BreastScreen van/clinic/hospital <input type="radio"/> Private clinic/radiologist <input type="radio"/> Other eg hospital	<input type="radio"/> BreastScreen van/clinic/hospital <input type="radio"/> Private clinic/radiologist <input type="radio"/> Other eg hospital not BreastScreen
E. If you had a mammogram in that year, what town or suburb did you have the mammogram?	_____	_____	_____
F. Were you pregnant that year?	<input type="radio"/> Yes <input type="radio"/> No	<input type="radio"/> Yes <input type="radio"/> No	<input type="radio"/> Yes <input type="radio"/> No
G. Were you taking birth control pills that year?	<input type="radio"/> Yes <input type="radio"/> No	<input type="radio"/> Yes <input type="radio"/> No	<input type="radio"/> Yes <input type="radio"/> No
H. Were you taking hormone replacement therapy (HRT) that year?	<input type="radio"/> Yes <input type="radio"/> No	<input type="radio"/> Yes <input type="radio"/> No	<input type="radio"/> Yes <input type="radio"/> No

Are there any other comments you would like to make about your experience of being diagnosed with DCIS?

Contact the Cancer Helpline on 13 20 11 (Freecall) if you feel that you would benefit by talking with someone else such as a counsellor about any feelings or concerns that you may have. The people who run this service are experienced in talking to women diagnosed with DCIS and breast cancer. They can offer you information and support. They can also give you information about health professionals such as counsellors, psychologists or psychiatrists who are experienced in talking with women in your situation.

You may also wish to talk about your feelings or concerns with your GP or you can ask your general practitioner to refer you to an appropriate health professional.

It is common for women to feel strong feelings and have concerns in your situation. **Help is available if you need it.** Don't put up with any feelings that you feel overwhelmed by.

**THANK YOU SO MUCH FOR YOUR TIME AND ENERGY
IN COMPLETING THIS SURVEY.**

***Please use the reply paid envelope to return completed survey to
NSW Cancer Registry Locked Mail Bag 1
Kings Cross NSW 1340***

**If you need any further information about the survey please contact
Ms Lesley Porter on Freecall 1800 500 105**

Appendix 2.7

Test-retest reliability of the developed survey items

A. Knowledge about DCIS

Table 1 outlines the test-retest reliability of the knowledge items (n=12) using the simple Kappa coefficient statistic (95% CL). The majority of knowledge items (75%) had an observed proportion of agreement of 83% or above, and 75% of knowledge items scored 0.52 or above in Kappa analysis. Agreement was found to be perfect (1.00) for 2 items (all participants responded *false* to *I had advanced breast cancer* item), almost perfect (0.81-0.99) for 2 items, substantial (0.61-0.80) for 3 items, moderate (0.41-0.60) for 4 items, and fair (0.21-0.40) for 1 item. The item found to be fair assessed knowledge about risk of local recurrence: *Even after treatment, there is still a chance that DCIS or breast cancer may come back in the breast (or in the chest wall if your breast was removed)*.

Table 1: Test-retest reliability of knowledge survey items

Knowledge	n sample	n agreement	observed proportion of agreement	simple kappa value	kappa (95% CL)
i I had breast cancer	33	32	94%	0.92	0.78-1.00
ii I had an early stage breast cancer	32	31	97%	0.90	0.70-1.00
iii I had a pre-cancer	29	24	83%	0.71	0.49-0.93
iv I had a non-invasive breast cancer	32	24	75%	0.52	0.25-0.80
v I had breast cancer that was contained in the milk ducts of my breasts	32	27	84%	0.59	0.28-0.90
vi I had an advanced breast cancer	31	31	100%	1.00	1.00
vii If left untreated, DCIS can develop into the type of breast cancer that can spread to other parts of the body	32	27	84%	0.43	0.07-0.79

continued next page

	Knowledge	n sample	n agreement	observed proportion of agreement	simple kappa value	kappa (95% CL)
viii	If left untreated, DCIS alone cannot spread to other parts of the body	32	24	75%	0.50	0.23-0.77
ix	<u>All</u> women diagnosed with DCIS if they are not treated will develop the type of breast cancer that can spread to other parts of the body	32	27	84%	0.73	0.51-0.94
x	The aim of treating DCIS is to remove the DCIS and prevent it from developing into the type of breast cancer that can spread to other parts of the body	32	32	100%	1.00	1.00
xi	Even after treatment, there is still a chance that DCIS or breast cancer may come back in the breast (or in the chest wall if your breast was removed)	32	22	69%	0.40	0.10-0.69
xii	I have a greater chance of developing breast cancer in the other breast than women who have not been diagnosed with DCIS	32	28	88%	0.80	0.62-0.98

B. Confusion about the diagnosis and treatment of DCIS

Table 2 outlines the test-retest reliability of the confusion items (n=7) using the weighted Kappa coefficient statistic (95% CL). All confusion items had an observed proportion of agreement of 73% or above, and 57% of confusion items scored 0.52 or above in Kappa analysis. Agreement was found to be substantial (0.61-0.80) for 1 item, moderate (0.41-0.60) for 3 items and fair (0.21-0.40) for 3 items. The items found to be fair assessed confusion about *the type of breast disease, why you needed the type of treatment you had, and the chances of your breast disease spreading to other parts of your body or dying from your breast disease after treatment*. However, the observed proportion of agreement for these items was 76%, 85% and 73% respectfully.

Table 2: Test-retest reliability of confusion survey items

Confusion	n sample	n agreement	observed proportion of agreement	weighted kappa value	kappa (95% CL)
i The type of breast disease you had	33	25	76%	0.30	-0.04-0.64
ii Whether or not you have the type of breast cancer that can spread to other parts of your body	32	28	88%	0.71*	0.44-0.97
iii The chances of your breast disease spreading to other parts of your body or dying from your breast disease if you did not have treatment	33	27	82%	0.53	0.22-0.82
iv The chances of developing breast cancer in the opposite breast	33	25	76%	0.54	0.24-0.83
v Why you needed the type of treatment you had	33	28	85%	0.38	0.01-0.75

continued next page

Confusion		n sample	n agreement	observed proportion of agreement	weighted kappa value	kappa (95% CL)
vi	The chance of developing breast cancer in the same breast or in the chest wall (if your breast has been removed)	31	23	74%	0.52	0.23-0.82
vii	The chances of your breast disease spreading to other parts of your body or dying from your breast disease after treatment	33	24	73%	0.40	0.10-0.70

*Simple kappa was used as weighted kappa was unable to be calculated because of the distribution of responses.

C. Satisfaction with information

Table 3 outlines the test-retest reliability of the information items (n=11) using the weighted Kappa coefficient statistic (95% CL). The majority of information items (82%) had an observed proportion of agreement of 72% or above, and 55% of information items scored above 0.50 in Kappa analysis. Agreement was found to be substantial (0.61-0.80) for 3 items, moderate (0.41-0.60) for 4 items, and fair (0.21-0.40) for 4 items. The items found to be fair assessed satisfaction with information about *all the possible treatment(s) for your breast disease*, *all the possible side effects of treatment(s) for your breast disease*; *the chances that the recommended treatment(s) would work*; and *how often you need check-ups*. However, the observed proportion of agreement for these items was 79%, 72% and 82% respectfully.

Table 3: Test-retest reliability of satisfaction with information survey items

Satisfaction with information		n sample	n agreement	observed proportion of agreement	weighted kappa value	kappa (95% CL)
i	The type of breast disease you had	33	27	82%	0.63	0.39-0.88
ii	Whether or not you have the type of breast cancer that can spread to other parts of your body	33	24	73%	0.51	0.25-0.76
iii	All of the possible treatments for your breast disease	33	24	73%	0.39	0.12-0.67
iv	All the possible side effects of treatment(s) for your breast disease	33	26	79%	0.10	-0.05-0.25
v	Breast reconstruction	32	25	78%	0.70	0.48-0.93
vi	The impact of your treatment(s) on your sexuality	31	20	65%	0.57	0.32-0.81
vii	The chances that the recommended treatment(s) would work	32	23	72%	0.30	-0.07-0.67
viii	The chances of developing breast cancer in your breast or chest wall (if your breast was removed) after treatment	31	24	77%	0.69	0.44-0.93
ix	The chances of your breast disease spreading to other parts of your body or dying from your breast disease if you did or did not have treatment	33	24	73%	0.58	0.34-0.82
x	The risk of your daughter(s) developing breast cancer	31	19	61%	0.49	0.23-0.75
xi	How often you need check-ups	33	27	82%	0.31	0.00-0.62

D. Perceived level of involvement in treatment decision-making

Table 4 outlines the test-retest reliability of the *perceived level of involvement in treatment decision-making* item using the weighted Kappa coefficient statistic (95% CL). Agreement was found to be moderate (0.41-0.60) with a low observed proportion of agreement (53%).

Table 4: Test-retest reliability of the perceived level of involvement in treatment decision-making survey item

	Perceived level of involvement in treatment decision-making	n sample	n agreement	observed proportion of agreement	weighted kappa value	kappa (95% CL)
i	How did you decide about treatment?	34	18	53%	0.48	0.25-0.72

E. Satisfaction with the perceived level of involvement in treatment decision-making

Table 5 outlines the test-retest reliability of the *satisfaction with the perceived level of involvement in treatment decision-making* item using the simple Kappa coefficient statistic (95% CL). Simple kappa was used as the weighted kappa was unable to be calculated because of the distribution of responses. Agreement was found to be moderate (0.41-0.60). However, the observed proportion of agreement was 88% for this item.

Table 5: Test-retest reliability of the satisfaction with the perceived level of involvement in treatment decision-making survey item

	Satisfaction with the perceived level of involvement in treatment decision-making	n sample	n agreement	observed proportion of agreement	simple kappa value*	kappa (95% CL)
i	How satisfied are you with how much you were involved in deciding about your treatment?	34	30	88%	0.43	-0.03-0.90

*Simple kappa was used as the weighted kappa was unable to be calculated because of the distribution of responses.

F. Worry relating to the DCIS diagnosis

Table 6 outlines the test-retest reliability of the worry items (n=4) using the weighted Kappa coefficient statistic (95% CL). The majority of worry items (75%) had an observed proportion of agreement of 76% or above, and all worry items scored 0.52 or above in Kappa analysis. Agreement was found to be substantial (0.61-0.80) for 2 items and moderate (0.41-0.60) for 2 items.

Table 6: Test-retest reliability of worry survey items

Worry relating to the DCIS diagnosis		n sample	n agreement	observed proportion of agreement	weighted kappa value	kappa (95% CL)
i	Your breast disease spreading to other parts of your body	33	25	76%	0.63	0.39-0.88
ii	Dying from your breast disease	33	26	79%	0.71	0.51-0.91
iii	Developing breast cancer in the same breast or in the chest wall (if your breast has been removed)	31	25	81%	0.52	0.23-0.82
iv	Developing breast cancer in the opposite breast	33	22	67%	0.55	0.31-0.80

G. Psychological support

Table 7 outlines the test-retest reliability of the psychological support items (n=3) using the simple Kappa coefficient statistic (95% CL). Agreement was found to be moderate (0.41-0.60) for 1 item and substantial (0.61-0.80) for 2 items.

Table 7: Test-retest reliability of psychological support survey items

Psychological support		n sample	n agreement	observed proportion of agreement	simple kappa value	kappa (95% CL)
i	Breast nurse	34	27	79%	0.58	0.30-0.86
ii	Counsellor	34	30	88%	0.76	0.55-0.98
iii	Psychologist or psychiatrist	34	32	94%	0.77	0.45-1.00

H. Type of Treatment

Table 8 outlines the test-retest reliability of the treatment items (n=7) using the simple Kappa coefficient statistic (95% CL). Agreement was found to be perfect (1.00) for 1 item (all participants responded *no* to *I had chemotherapy* item), almost perfect (0.81-0.99) for 4 items, substantial (0.61-0.80) for 1 item, and moderate (0.41-0.60) for 1 item.

Table 8: Test-retest reliability of treatment survey items

Treatment		n sample	n agreement	observed proportion of agreement	simple kappa value	kappa (95% CL)
i	I had a lumpectomy (only part of my breast was removed)	34	32	94%	0.87	0.70-1.00
ii	I had a mastectomy (my whole breast was removed)	34	33	97%	0.93	0.81-1.00
iii	The lymph nodes under my arms were removed	34	32	94%	0.82	0.58-1.00
iv	I had radiotherapy	34	30	88%	0.76	0.55-0.98
v	I had chemotherapy (drug treatment)	34	34	100%	1.00	1.00
vi	I had hormonal drugs (eg Tamoxifen)	34	33	97%	0.84	0.54-1.00
vii	I didn't have treatment	34	32	94%	0.47	-0.16-1.00

Appendices Chapter 4

Appendix 4.1



DCIS Communication Project

St Vincent's BreastScreen

PROTOCOL FOR BREASTSCREEN COUNSELLORS

A mobile phone will be supplied to the BreastScreen counsellors and the research nurse for the purposes of this study.

The research nurse's, Alice Renwick, mobile phone number: 0400 570 196

Simone De Morgan's contact phone number: (02) 9665 7306 or email simoned@ihug.com.au

Women will be eligible to receive information about the study if:

1. They have lesions on their mammogram suspicious of DCIS eg calcifications
2. They will be receiving their biopsy results at the St Vincent's BreastScreen clinic
3. They do not require an interpreter
4. They do not have a psychiatric illness

Step 1

- During the consultation in which the BreastScreen counsellor consents eligible women to having a biopsy, the BreastScreen counsellor will *briefly* explain that there is a study being conducted about how doctors communicate with patients and that some women will be asked to participate when they come back to get their biopsy results.
- The BreastScreen counsellor will give eligible women an information sheet about the study to take away with them.

- The BreastScreen counsellor will record the full name (including first name) of any woman who at this stage declines participation in the study. The BreastScreen counsellor will not ask the woman directly if she wishes to participate in the study. However, if the woman says she is not interested in the study she will record her name. The BreastScreen counsellor will ensure that the woman's name and time of her consultation is not given to the research nurse.

Step 2

- The research nurse will ring the BreastScreen counsellor on the mobile phone after 10am on the morning of the clinic with a consenting surgeon and ask the BreastScreen counsellor whether any eligible women will be coming in that day. (The BreastScreen counsellor will confirm the diagnosis of patients with the radiologist.) The research nurse will record the name(s) of any eligible women and the time of her/their consultation(s).

PLEASE NOTE: The BreastScreen counsellor will select, in consultation with the radiologist, all women with DCIS and 1-3 women (in total) with benign breast conditions. However, she will NOT tell the research nurse of the woman's diagnosis. She will just tell the research nurse that an ELIGIBLE women is coming into the clinic.

Step 3

- At the end of the consultation, the surgeon will give one audio-tape to the woman and one audio-tape to the research nurse.
- The BreastScreen counsellor at the beginning of her consultation with the woman will:
 - Explain to women with DCIS that the aim of the study is actually to see how doctors communicate to women diagnosed with their type of breast disease ie DCIS but that this was not said before their consultation as the researchers felt that it was important that the person who delivered the diagnosis was the surgeon.
 - Give the second audio-tape back to women with benign breast conditions and explain to them that the study is looking at how doctors communicate with women with a particular breast disease called DCIS but that this could not be said to women before their consultation with the surgeon.

Step 4

- The **research nurse** will be responsible for the audio-tapes from women with DCIS. The research nurse will put all consent forms and surveys in a file in the **BreastScreen counsellor's** office. At the end of the study period the consent forms and surveys will be collected.



Appendix 4.2

DCIS Communication Project

St Vincent's BreastScreen

PROTOCOL FOR RESEARCH NURSE

A mobile phone will be supplied to the BreastScreen counsellors and the research nurse for the purposes of this study.

The research nurse's, Alice Renwick, mobile phone number: 0400 570 196

Simone De Morgan's contact phone number: (02) 9665 7306 or email simoned@ihug.com.au

Step 1

- The research nurse will assist in acquiring the audio-tape recorder and audio-tapes for the study.
- The research nurse will be responsible for the audio-tape recorder and setting up the audio-tape recorder in the surgeon's clinic room.

Step 2

- The research nurse will ring the BreastScreen counsellor on the mobile phone after 10am on the morning of the clinic with a consenting surgeon and ask the BreastScreen counsellor whether any eligible women will be coming in that day. (The BreastScreen counsellor will confirm the diagnoses of patients with the radiologist). The research nurse will record the name of the woman and the time of her consultation.

PLEASE NOTE: The BreastScreen counsellor will NOT tell the research nurse the woman's diagnosis. She will just tell the research nurse that an ELIGIBLE woman is coming into the clinic.

Step 3

- The research nurse will arrive 20 minute prior to the consultation between the eligible woman and the surgeon.
- She will collect the labeled folder containing women's consent forms and surveys in the file in the BreastScreen counsellor's office.
- She will call the woman into a private room and:
 - Explain the purpose of the study: *"This study will look at how doctors communicate with women when they are giving them their test results. The results of the study will be used to develop ways to improve how doctors communicate to women."*
 - Explain to the woman what the study entails: *"If you consent to the study the conversation with the surgeon will be audio-taped"*.
 - Inform the woman that she will receive a copy of her audio-tape at the end of the consultation which most women find valuable.
 - Explain to the woman that *"All the information you provide will be kept strictly confidential. The researcher who hears the audio-tape of your consultation will not know who you are. You will not be able to be identified, either directly or indirectly, when the results of the study are reported"*.
 - Explain to the woman that not consenting to the study will not affect her medical care in any way
 - Explain to the woman that she may stop the audio-taping at any time and that she may decline giving a copy to the surgeon at the end of the consultation.
 - If the woman is willing to participate in the study:
 - give her the **consent form**
 - read through the points on the consent form with her
 - direct her to put her name on the consent form and to sign the consent form
 - direct her to record her address if she wishes for the results of the study to be sent to her

- If the woman is willing to participate in the study, ask the woman to complete a **one-page survey**
- Answer any questions
- If the woman asks the research nurse her diagnosis, the research nurse will tell her that she “*does not know her diagnosis*”

Step 4

- Thank the woman for participating in the study (if she has consented) and inform her that the surgeon will shortly call her into the consultation. She will then hand over to the BreastScreen counsellor.

Step 5

- Before the consultation the research nurse will inform the surgeon if the woman has consented to the study. She will show the surgeon the woman's signed consent form and give the surgeon a comment sheet for any additional comments. The codes on the comment sheet will be the same as on the labels on the audio-tapes.
- She will also set up the audio-tape recorders and ensure that two audio-tapes are in the recorders. She will not be present during the consultation.
- She will then return the folder containing the consent forms and surveys to the BreastScreen counsellor's office unless another eligible woman is attending the clinic that day.
- She will send the audio-tape by registered post to the researcher who will transcribe the audio-tape.

Step 6

- The research nurse will record how many consultations each surgeon has audio-taped. After three consultations per surgeon have been audio-taped, if the surgeon consented to participating in the interview, the research nurse will liaise with the surgeon and the interviewer to establish the best time for the 20 minute interview.

Appendix 4.3

Research Nurse Refusal Form

St Vincent's BreastScreen

[illegible]

Appendix 4.4

Patient Code Log Form

St Vincent's BreastScreen

(only for women who consent to the study)

[illegible]

Appendix 4.5

Surgeon Code Log Form

St Vincent's BreastScreen

[illegible]



Appendix 4.6

DCIS Communication Project

Background and aims of the study

St Vincent's BreastScreen

Introduction

Ductal carcinoma in situ (DCIS) is a non-invasive variant of breast cancer. A growing number of women are diagnosed with DCIS through the national mammographic screening program. While these women do not have invasive breast disease, many will undergo breast surgery and radiotherapy. Draft clinical practice guidelines for the management of DCIS developed by the National Breast Cancer Centre indicates that the natural history of DCIS is uncertain and that there is only limited evidence about the benefit of treatment for all types of DCIS.

A recent qualitative study by the National Breast Cancer Centre explored women's experiences of being diagnosed with DCIS¹. The study highlights the confusion, anxiety and difficulty in treatment decision-making women experienced after a diagnosis of DCIS. Although DCIS is a non-invasive breast disease that cannot of itself metastasise to other parts of the body, this study found that women were confused about whether or not they had cancer that could result in death. Women's confusion was compounded by the use of the term 'carcinoma' and by treatment options such as mastectomy being recommended.

The proposed project

Although research has shown that good communication improves patient outcomes, there is little research about clinician-patient communication when the evidence of benefit of treatment is emerging and the natural history is uncertain. The proposed project aims to explore communication around these conditions using DCIS as an example. Although the project will focus on DCIS, it is anticipated that the findings will be relevant to other areas where evidence about treatment effectiveness is emerging.

The proposed project will initially describe current clinician-patient communication about DCIS and explore clinicians' perceptions of the experience of communicating a diagnosis of DCIS and treatment options to women. The results of the study will be used to develop a clinician-administered visual communication tool for patients diagnosed with DCIS. The communication tool

¹ De Morgan S, Redman S, White K, Cakir B, Boyages J. Well have I got cancer or haven't I?: The psycho-social issues for women diagnosed with ductal carcinoma in situ (DCIS). *Health Expectations* 2002; 5: 310-318.

aims to improve patient outcomes such as patient understanding, satisfaction with care, physical health and psychological adjustment.

Audio-taping consultations between doctors and patients is common in many areas of research. An important advantage of audio tapes over participant reports is their reliability; reports of events from patients often differ from actual occurrences. In this study we are replicating a methodology used in a study of 1057 audio-taped consultations between doctors and patients, many of which were initial consultations between patients and surgeons.²

Proposed methodology

Design:

The study involves two parts:

Part A involves **audio-taping and analysis of initial diagnostic (biopsy-result) consultations** with surgeons and women diagnosed with DCIS. Each surgeon will be asked to audio-tape 2-3 consultations.

Aim:

- ◆ To describe current communication about DCIS in relation to the following how the nature of DCIS, prognosis and treatment options is communicated to women diagnosed with DCIS

Part B involves 20-30 minute **semi-structured interviews** with surgeons about their experiences of discussing a diagnosis of DCIS and treatment options to women (after Part A of the study is completed).

Aim:

- ◆ To explore whether any difficulties are experienced in relation to communicating a diagnosis and treatment options to women with DCIS and whether surgeons find visual aids useful.

Surgeons may participate in either or both parts of the study.

² Braddock CH (III), Edwards KA, Hasenberg NM, Laidley TL, Levinson W. Informed decision making in outpatient practice. Time to get back to basics. JAMA 1999; 282: 213-20.



DCIS Communication Project

St Vincent's BreastScreen Brief outline of methodology

Step A

During the consultation in which the **BreastScreen counsellor** consents eligible women to having a biopsy, the BreastScreen counsellor will *briefly* explain that there is study being conducted about how doctors communicate with patients and that some women will be asked to participate when they come back to get their biopsy results. The BreastScreen counsellor will give eligible women an information sheet about the study to take away with them.

Step B

The **research nurse** will ring the **BreastScreen counsellor** on the mobile phone provided after 10am on the morning of the clinic with a consenting surgeon and ask the BreastScreen nurse counsellor whether any eligible women will be coming in that day. *[Eligible women will be determined by the radiologist and will have DCIS or a benign breast condition (only 2-3 women with benign breast conditions will be selected for the whole study period) and will not require an interpreter or have a major psychiatric illness]*. The research nurse will record the name of the eligible woman and the time of her consultation.

Step C

The **research nurse** will arrive 20 minute prior to the consultation between the eligible woman and the surgeon. She will call the woman into a private room, explain the purpose of the study, answer any questions and obtain consent from the woman. If the woman consents she will complete a written consent form and a one-page survey.

Step D

Before the consultation with the **surgeon**, the research nurse will inform the surgeon if the woman has consented to the study. She will show the surgeon the woman's signed consent form. She will also set up two audio-tape recorders and

ensure that audio-tapes are in the recorders. She will not be present in the consultation.

Step E

The **surgeon** will turn on both audio-tapes at the beginning of the consultation and turn off both audio-tapes at the end of the consultation. The surgeon will give one audio-tape to the woman and one audio-tape to the **research nurse**.

Step F

The **BreastScreen counsellor** at the beginning of her consultation with the woman will:

- Explain to women with DCIS that the aim of the study is actually to see how doctors communicate to women diagnosed with their type of breast disease ie DCIS but that this was not said before their consultation as the researchers felt that it was important that the person who delivered the diagnosis was the surgeon.
- Give the second audio-tape back to women with benign breast conditions and explain to them that the study is looking at how doctors communicate with women with a particular breast disease called DCIS but that this could not be said to women before their consultation with the surgeon.

Step G

The **research nurse** will be responsible for the audio-tapes from women with DCIS. The research nurse will put all consent forms and surveys in a file in the **BreastScreen counsellor's** office. At the end of the study period the consent forms and surveys will be collected.

Step H

After 2-3 consultations per **surgeon** have been audio-taped the **research nurse** will contact the surgeon, if the surgeon has consented to participating in the interview, and ask the surgeon what the best time and day is for the 20 minute interview and record the surgeon's contact details.



DCIS Communication Project

More information for surgeons

St Vincent's BreastScreen

Need more information?

You may telephone the Senior Project Officer, Simone De Morgan on **(02) 9665 7306** if you would like more information about the study.

Ethical Guidelines

This study has been approved by the Ethics Committee of the St Vincent's Hospital and The Cancer Council Victoria Human Research Ethics Committee. The study will be carried out according to the National Statement on Ethical Conduct on Research Involving Humans (June 1999) produced by the National Health and Medical Research Council of Australia.

Concerns and complaints about how the study has been carried out?

If you have any concerns or complaints about how the study has been carried out you can contact Ms Jill Hambling, Administration Officer, Research and Grants Unit, St Vincent's Hospital on (03) 9288 3930 or write to her at the Research and Grants Unit, St Vincent's Hospital, Ground Floor, Healy Building, 41 Victoria Parade, Fitzroy, Vic 3065.

If you have any concerns or complaints you may also contact the Head of the Research Management Unit at The Cancer Council Victoria, Ms Woody Macpherson, on (03) 9635 5100 or write to her at The Cancer Council Victoria at 1 Rathdowne Street, Carlton VIC 3053.

How can I find out about the results of the study?

The results of the study will be presented to staff at the BreastScreen service. The report from the study will also be available to staff who are interested.

Appendix 4.7



Consent form for surgeons

I (name) _____

[Please tick one, both or neither box]

☐ **Consent to having 2-3 consultations with patients audio-taped**

☐ **Consent to participating in a 20 minute interview about my experience of communicating a diagnosis of DCIS to women**

I am aware that:

- I have the right to decline giving a copy of the audio-tape to the researcher at the end of the consultation
- My name will not be written on any label on the audio-tape
- If my name is mentioned in the audio-tape the researcher who transcribes the audio-tape will not record my name so that I cannot be identified in the analysis
- My name will not be recorded on any written notes (or any label on an audio-tape) taken from the interview about my experiences of DCIS communication
- All the results of this study will be published in a form that will not allow me to be identified
- I have a right to withdraw from the study at any point after giving initial consent (and any material already given to researchers will be destroyed so that it is not used in the final analysis of results)

Signature _____

Date _____

Phone contact details for interview

Work _____

Mobile _____

Appendix 4.8



St Vincent's BreastScreen

Survey for surgeons

(Surgeon's code _____)

For this study we would like some information about you and your practice. This information is confidential. Please answer every question.

- 1 **What is your gender?**
 - ☐ Female
 - ☐ Male
- 2 **How old are you?**
 - ☐ <30 years
 - ☐ 31-40 years
 - ☐ 41-50 years
 - ☐ 51-60 years
 - ☐ >61years
- 3 **How many years have you been practicing as a breast surgeon?**
 - ☐ 0-5 years
 - ☐ 6-10 years
 - ☐ 11-15 years
 - ☐ >15 years
- 4 **Is English your first language?**
 - ☐ Yes
 - ☐ No
- 5 **Approximately how many newly diagnosed breast cancer patients do you see per year (including DCIS patients)? _____**
- 6 **Approximately how many newly diagnosed DCIS patients do you see per year? _____**

THANK YOU FOR YOUR TIME AND ENERGY IN COMPLETING
THIS INFORMATION SHEET

Appendix 4.9



DCIS Communication Project

St Vincent's BreastScreen

PROTOCOL FOR BREASTSCREEN SURGEONS FOR AUDIO-TAPING STUDY

Step 1

- All surgeons who wish to participate in the study will complete a consent form and one-page survey.

Step 2

- Before the consultation, the research nurse will notify the surgeon if the woman has consented to the study. The research nurse will show the surgeon the woman's signed consent form. She will also set up the audio-tape recorders and ensure that two audio-tapes are in the recorders. She will not be present during the consultation.

Step 3

- The surgeon will **turn on both audio-tapes** at the beginning of the consultation.
- The surgeon will **turn off both audio-tapes** at the end of the consultation.

Step 4

- The surgeon will give one audio-tape to the woman and one audio-tape to the research nurse.

Step 5

- After the consultation, if the surgeon wishes to make any additional comments about the audio-taped interview, a comment sheet is provided. The surgeon will be responsible for giving this comment sheet to either the research nurse or the BreastScreen counsellor.

Step 6

- After 2-3 consultations have been audio-taped the research nurse will contact the surgeon, if the surgeon has consented to participating in the interview, and ask the surgeon what the best time and day is for the 20 minute interview and record the surgeon's contact details.

Appendix 4.10



St Vincent's BreastScreen

Additional Comment Sheet for surgeons

To be given to BreastScreen counsellor or research nurse

Code on labels of audio-tapes _____

Are there any comments you would like to make about the audio-taped consultation with a woman diagnosed with DCIS?

Appendix 4.11



St Vincent's BreastScreen

Communication Project *Information about the study for women*

Why is the study being done?

This study will look at how doctors communicate with women and how they respond to women's questions and concerns. We know from other studies that the way in which doctors communicate is important. If we knew more about how doctors communicate with women when giving their results we could help improve doctors' communication. The results of the study will be used to develop ways to improve how doctors communicate to women.

We hope this will help improve women's well-being and how they feel about their care.

Who is conducting the study?

BreastCare Victoria, the National Breast Cancer Centre and St Vincent's BreastScreen are conducting the study.

What will you be asked to do?

When you get the results you may be asked if you are willing for your conversation with the surgeon to be audio-taped.

If you consent, the research nurse will give you a copy of the audio-tape to take home with you and she will keep a copy of the audio-tape for the study. Most women find that having a copy of their audio-tape is valuable and that it increases their ability to remember what was said in the consultation.

Only some women will be asked to participate in the study. **If** you are asked to participate in the study this does not mean that you have cancer. **If** you are asked to participate in the study a research nurse, Mrs Alice Renwick, will approach you at the time of your consultation with a surgeon in which you will get your results. She will ask for your written consent to audio-taping the consultation with your surgeon. **The research nurse will not know what your diagnosis is.** If you consent, she will also ask you to complete a brief survey that should only take a few minutes to complete.

Will the information be kept confidential?

Yes. All the information you provide will be kept strictly confidential. The researcher who hears the audio-tape of your consultation will not know who you are. You will not be able to be identified, either directly or indirectly, when the results of the study are reported.

What if you don't agree to take part?

Participation in this study is entirely voluntary. The treatment and the care given to you will not be affected in any way if you choose not to take part in the study.

You also have the right to turn-off the audio-tape at any time during the consultation. You can decide at the end of the consultation that you do not want the audio-tape to be included in the study and can take both audio-tapes home with you.

If you decide before you leave the clinic today that you do not wish to participate in the study you can tell one of the BreastScreen counsellors: Heather, Marilyn, Sharon or Melanie

Need more information?

You can call the research nurse, Mrs Alice Renwick, on **0400 570 196** at any time about the study. You may also ask her any questions **if** you are approached by her at the time of your consultation with a surgeon when you will get the results. The research nurse will answer any questions you may have and you are free to say no to participating in the study.

Ethical Guidelines

This study has been approved by the Ethics Committee of the St Vincent's Hospital and The Cancer Council Victoria Human Research Ethics Committee. The study will be carried out according to the National Statement on Ethical Conduct on Research Involving Humans (June 1999) produced by the National Health and Medical Research Council of Australia.

Concerns and complaints about how the study has been carried out?

If you have any concerns or complaints about how the study has been carried out you can contact the Patient Representative at St Vincent's Health on (03) 9288 2211. You will need to tell the Patient Representative the name of the principal investigator for the study, Professor Sally Redman.

If you have any concerns or complaints you may also contact the Head of the Research Management Unit at The Cancer Council Victoria, Ms Woody Macpherson, on (03) 9635 5100 or write to her at The Cancer Council Victoria at 1 Rathdowne Street, Carlton VIC 3053.

How can I find out about the results of the study?

If you consent to participating in the study, the research nurse will ask you whether you wish to be sent the results of the study. If so, she will record your name and address on your consent form.

Thank you for reading this information sheet.

We hope that this research project will help other women in the future.

The Research Team

National Breast Cancer Centre

Professor Sally Redman

Ms Simone De Morgan

St Vincent's BreastScreen

Dr Jennifer Cawson

Postal address

Communication Project

National Breast Cancer Centre

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Appendix 4.12

Survey for women

St Vincent's BreastScreen: Code number on label of audio-tapes _____

For this study we would like some information about you. This information is confidential. For each question, please tick ONE answer that best suits you. Please answer every question.

- 1 **What is your date of birth?**
____/____/____
- 2 **What is the postcode of the suburb you live in?** _____
- 3 **Is English your first language?**
 - ☐ Yes
 - ☐ No
- 4 **Are you Aboriginal or Torres Strait Islander origin?**
 - ☐ Yes
 - ☐ No
- 5 **Which of the following best describes your highest education level?**
 - ☐ Primary school only
 - ☐ Some secondary school
 - ☐ School Certificate /Year 10 / 4th form / Intermediate certificate
 - ☐ HSC / Year 12 / 6th form / Leaving Certificate
 - ☐ College (Diploma or Certificate) eg TAFE, business college
 - ☐ University (Degree)
- 6 **Which of the following best describes your present relationship status?**
 - ☐ Married
 - ☐ De facto or living with a partner
 - ☐ Divorced or separated
 - ☐ Widowed
 - ☐ Single
 - ☐ In a relationship but not living with my partner
- 7 **Are you bringing along a support person into the consultation with the surgeon today?**
 - ☐ Yes
 - ☐ No

If Yes, what relationship does this person or people have to you eg your partner, sister, friend? _____

8 Which of the following best describes your **USUAL** work situation?

- ☐ Home duties
- ☐ Retired
- ☐ Self-employed
- ☐ Employed: Full-time
- ☐ Employed: Part-time or casual
- ☐ Looking for work or unemployed
- ☐ Student
- ☐ Physically or mentally unable to work
- ☐ Other _____

9 What is your usual occupation? (if retired, looking for work or unable to work what was your most recent past occupation)

10 How do you prefer to make decisions about any treatment that you may need? Please tick **ONE** answer below.

- ☐ I prefer the doctor to make the decision using all that he or she knows about treatments
- ☐ I prefer the doctor to make the decision but strongly consider my opinion
- ☐ I prefer the doctor and I to make the decision together on an equal basis
- ☐ I prefer to make the decision but strongly consider the doctor's opinion
- ☐ I prefer to make the decision using all that I know and learn about the treatments

Appendix 4.13



St Vincent's BreastScreen

Woman's consent form

I (name) _____

☐ **Consent**

☐ **Do not consent**

to participate in the study and to have my consultation with the surgeon
audio-taped

I am aware that:

- Not participating in the study will not affect my care in any way
- I have the right to turn-off the audio-tape at any time during the consultation
- I have the right to decline giving my audio-tape to the researcher at the end of the consultation
- The audio-tape will be de-identified so that the researcher who hears the audio-tape will not know who I am
- All the results of this study will be published in a form that will not allow me to be identified
- I will be given a copy of the audio-tape to take home with me

Signature _____

Date _____

Address (if you wish the results of the study to be sent to you)

Appendix 4.14

DCIS audio-tape study

“Well, have I got cancer or haven’t I?” How well do clinicians communicate a diagnosis of ductal carcinoma in situ (DCIS) with women?

Coding Manual

Audio-tapes coded (Surgeon code/Patient code):

1	Eg 4L	16
2		17
3		18
4		19
5		20
6		21
7		22
8		23
9		24
10		25
11		26
12		27
13		28
14		29
15		30

Audio-tapes that were not coded (excluded):

1	Eg 4L	Reason:
2		
3		
4		
5		

Terms used to describe diagnosis		Code of Surgeon Woman	Example
i	DCIS	Eg 9L	Eg 9L call it DCIS for short because it's quite, um, hard to say, that whole thing
ii	Ductal carcinoma in situ or carcinoma in situ or in situ cancer	Eg 4L	Eg 4L it's something called Ductal Carcinoma in Situ
iii	Pre-cancer or pre-cancerous condition	Eg 2P	Eg 2P we would call a pre-cancerous changes in the breast
iv	different type of / type of breast cancer/cancer	Eg 18B	Eg 18B what that means is that there are cancer cells in the specimen but it's a special type of cancer which is a little different to what you imagine when you imagine a kind of a lump is breast cancer, different to the type of cancer when you think 'Oh, gee, you know, cancer can pop up in other places at other times.'
v	Non-invasive breast cancer	Eg 15B	Eg 15B before we had breast screen we used to see kind of fewer non-invasive cancer in about 5 out of 100 cases of breast cancer. But now we see them close to a quarter.
vi	Very early/early breast cancer	Eg 9F	Eg I'm afraid they did show early evidence of cancer the one in the front of the breast showed an early cancer at a stage before it has begun to spread beyond the breast.
vii	very early stage or early stage (no cancer)	Eg 9L	Eg 9L because it's all very early stage.
viii	Contained	Eg 13I	Eg 13I They're only still in the duct. <i>Contained</i> Contained in the duct, they haven't developed the ability yet to get out of the duct and get to other parts of the breast or other parts of the body.
ix	Tumour	Eg 4C	Eg 4C You've got a type of tumour. It's probably, most of us would consider it not a true cancer that could be lethal, but it's something that needs to be dealt with.

x	Cancer cells	Eg 9L	Eg 9L They really are cancer cells but they're all trapped within the duct.
xi	Abnormal cells/abnormality	Eg 2P	Eg 2P It's abnormal, it shows some changes; the cells themselves show abnormalities)
xii	Other	Eg 2P	Eg 2P shows some changes; it hasn't <u>turned into a full blown cancer</u>

Key DCIS Communication Elements

A	Information-giving behaviours	Yes No (and categories or notes if appropriate)	Code of Surgeon Woman	Example (and notes if appropriate such as if woman initiated conversation; or if Element communicated unclearly; or a summary of the communication)
1	Reassure the woman that she <u>does not</u> have breast cancer as we commonly understand it, that is, invasive breast cancer	Eg yes	Eg 2P	Eg 2P It's abnormal, it shows some changes. (mmm) which – um – we would call a pre-cancerous changes in the breast. In other words, it hasn't turned into a full blown cancer, but the cells themselves show abnormalities.
2	Tell the woman she has ductal carcinoma in situ or DCIS or carcinoma in situ	Eg yes	Eg 4L	Eg 4L: it's something called Ductal Carcinoma in Situ
3	Explain how DCIS differs from invasive breast cancer:			
i	Explain that DCIS cannot spread to other parts of the body unlike invasive breast cancer	Eg yes	Eg 9L	Eg 9L: They really are cancer cells but they're all trapped within the duct. (Oh, right, mmm) And it's when it gets through the wall of the duct that we call it invasive cancer or true cancer of the breast. (mmm. So is mine still within the duct) From what we can see. Now as you know they've some cores (mmm) And in all of those cores they've only seen this Ductal Carcinoma in Situ. They haven't seen any invasive malignancy. (later) Yeah. It's really only once it's through the wall of the duct that it has the potential to spread into [unclear] to the rest of the breast.

ii	Explain that DCIS cannot cause death unlike invasive breast cancer	Eg yes	Eg 9L	Eg 9L: the ductal carcinoma in situ is rarely the, it shouldn't, you know, cause you to die because it's all very early stage.
iii	Explain the tissue pathology, that is, that the abnormal cells are contained in the milk ducts of the breast in DCIS unlike in invasive breast cancer in which they have spread outside the milk ducts	Eg yes	Eg 9L	Eg 9L: So what that is, if you have a look at this picture of the breast you can see all the, um, ducts branching away (mmm) from the nipple and they divide and that's what makes the milk. (mmm) If you look at one of those ducts in cross section normally (mmm) um, it's lined by one layer of pretty regular looking cells. (mmm) ah, they all look very much the same. In this ductal carcinoma in situ, or DCIS for short, ah, the cells within the ducts have started multiplying, so they look very abnormal (mmm) They really are cancer cells but they're all trapped within the duct. (Oh, right, mmm) And it's when it gets through the wall of the duct that we call it invasive cancer or true cancer of the breast
4	Explain the natural history of DCIS:			
i	Explain DCIS either as a <u>precursor</u> to invasive breast cancer OR Explain DCIS as a <u>risk</u> for developing invasive breast cancer	Eg Yes explicitly uses terms DCIS and invasive bc	Eg 4L	Eg 4L: now we think that probably if we left Ductal Carcinoma in Situ, it may go on to invasive cancer.
		Eg Yes uses terms such as pre-cancer and developing into cancer	Eg 8K	Eg 8K: Now, if you stop and think about it, pre-cancer will only cause troubles when it turns into cancer.
5	Explain the uncertainty relating to the natural history of DCIS:			
i	Explain that not all women with DCIS will develop invasive breast cancer if they are not treated, that is, some women with DCIS will never develop breast cancer if they are not treated OR may or may not develop into IBC	Eg yes	Eg 4L	Eg 4L: In a few people who, they have left it in the past, not everyone does go on to get invasive cancer. I mean maybe 30 or 40 percent of people go on over the next 10 years to develop invasive cancer. But obviously we're concerned enough about it that we recommend that that area be removed.

		Eg Says <u>will</u> progress	Eg 6P	Eg 6P: We, we know that if, if nothing is done, or we believe that this will progress no matter, will eventually turn into a full blown cancer if nothing was done
ii	Explain the uncertainty about which DCIS women would develop invasive breast cancer	Eg yes	Eg18B	Eg 18B: And so that – these type of cancer cells actually can't get out of the milk duct and form a lump in the tissue. Some of them, if we leave them, will change enough to be able to kind of break down that, that membrane and get out and make a lump in the tissues. Some of them probably would stay within the milk duct forever. And we don't actually know how to tell the difference between the two.
iii	Explain the uncertainty about the proportion of DCIS women who would develop invasive breast cancer	Eg yes	4L	4L: In a few people who, they have left it in the past, not everyone does go on to get invasive cancer. I mean maybe 30 or 40 percent of people go on over the next 10 years to develop invasive cancer. But obviously we're concerned enough about it that we recommend that that area be removed.
iv	Explain the uncertainty about how long after the DCIS diagnosis invasive breast cancer would develop	Eg yes	Eg 7G;	Eg 7G: So the treatment for this – and why do we treat it? We treat it – if we don't treat it, there's a chance that this non-invasive cancer will progress and become an invasive cancer at some stage down the track . That varies – I mean, one in five ladies that will happen, the other five, the other four, one in five ladies will have the cancers become invasive, four may not have any problems at all. We don't know what's going to happen to yours. So we would recommend to you that we do do some treatment for this. The treatment that we would recommend would be firstly, is to remove the area.
6	Explain the provisional nature of prognostic information:			
i	Explain that more information will be obtained when the pathologist examines the breast tissue removed during surgery	Eg yes	Eg 4L	Eg 4L: mentions more info, affect decisions, size, margins, grade;) it looks like it's a reasonably small area. Maybe about a centimetre or so. (Mmm) So there's no reason to think you need a mastectomy for example. It should be easily removed, ah, just, ah, removing the calcifications in a rim of normal breast tissue around it. Um – obviously the pathologist will need to look to make sure

				that there's a rim of normal breast tissue around it (Mmmm) So that none is left behind (Mmmm) And then, depending on the final results, how big it is, um, if, and, ah, something called the grade. Which is sort of what it looks like under the microscope, sometimes some radiotherapy is recommended is recommended as well, just to decrease the risk of it coming back again.
ii	Explain that the information in the pathology report will affect decisions about treatment	Eg yes	Eg 4L	
iii	Explain that the pathology report after surgery will report on the features of the DCIS such as the size, grade, margins	Eg Yes	Eg 4L	
iv	Explain that the pathological features such as grade, size, margins <u>increase the risk</u> of developing invasive breast cancer and DCIS coming back in the breast	Eg yes	Eg 4L	Eg 4L: (surgeon talks about it increases risk of it coming back but not invasive breast cancer) Um – obviously the pathologist will need to look to make sure that there's a rim of normal breast tissue around it (Mmmm) So that none is left behind (Mmmm) And then, depending on the final results, how big it is, um, if, and, ah, something called the grade. Which is sort of what it looks like under the microscope, sometimes some radiotherapy is recommended is recommended as well, <u>just to decrease the risk of it coming back again.</u>
v	Explain that invasive breast cancer may be found during surgery	Eg yes	Eg 4L	Eg 4L: (ibc) Very occasionally we find that once we've removed that area there is a little bit of invasive cancer within what we've taken out. Um – that's pretty unusual, but occasionally we do find that's the case.(mmmm) But, um, from what we've got so far on the biopsies, all they've seen is the Ductal Carcinoma in Situ.
vi	Explain that if invasive breast cancer is found during surgery that this will affect decisions about	Eg yes	Eg 9L	See above

treatment				
		Eg n/a	Eg 2P	
vii	Reassure the woman that, at this stage, she does not have invasive breast cancer	Eg yes	Eg 10K	See above
		Eg n/a	Eg 2P	
7	Explain the aim and importance of treatment:			
i	Explain that treatment for DCIS aims to remove the DCIS to help prevent invasive breast cancer from developing in the breast OR that in most women treatment for the DCIS results in complete cure. However, if the DCIS is not treated it can develop into invasive breast cancer which is a serious condition that can spread and cause death. Therefore, treatment is highly recommended for DCIS.	Eg Yes Explicit Words: to prevent invasive breast cancer or cancer	Eg 4L	Eg 4L: now we think that probably if we left Ductal Carcinoma in Situ, it may go on to invasive cancer. So we would normally recommend to have some treatment to prevent that happening
		Eg Yes But not explicit Words: Does not progress; does not cause problems in future	Eg 2P	Eg 2P: Women initiates statements : (woman) well, I suppose it can be it's getting there early isn't it and removing it early before it becomes full grown – is that right?(dr)That's, that's what we're aiming to achieve
8	Reassure the woman of an excellent prognosis after treatment:			
i	Explain that most women diagnosed and treated for DCIS will not develop invasive breast cancer or DCIS again in that breast	Eg yes	Eg XE	Eg XE: When these cancer changes are in the milk ducts they can be totally cured by removing the area. Alright?OK [sounds uncertain]As simple as thatOKf there is invasion into the tissues it gets a little bit more complicated, but as long as

OR that treatment for DCIS usually results in a low risk of developing invasive breast cancer or of the DCIS coming back Or that in most women treatment for the DCIS results in complete cure.	it is confined within the milk ducts, simply removing the area will cure that particular problem.OK It does leave people who have this problem with an increased risk of getting some further cancer changes in the future, in other areas of the breast, or the other breast, a bit more than the average risk, but not hugely high, but something that you will need to discuss or talk about and keep an eye on in the future (later) Um – OK. Um. Probably the bottom line in all this is, while you’ve got to have the treatment, and deal with it, it is a totally curable good state of affairs. And that’s the good news part, and it’s good that you’ve found it now
---	---

B	Communication behaviours: Facilitating understanding	Yes No	Code of Surgeon Woman	
1	Use diagrams of DCIS and invasive breast cancer in the breast		Can be more than one per consultation	
i	uses diagram		Eg 4L	
ii	draws diagram		Eg 15B	
iii	uses mammogram		Eg 18B	
		None	Eg 2P	
2	Check the woman’s understanding about how DCIS differs from invasive breast cancer	Yes No (and categories or notes if appropriate)	Code of Surgeon Woman	Example (and notes if appropriate such as if woman initiated conversation; or if Element communicated unclearly; or a summary of the communication)
i	check understanding eg how it differs from invasive breast cancer, natural history of DCIS	Eg Yes but doesn’t get woman to explain	Eg 18B	Eg 18B: (check’s understanding but doesn’t get woman to explain it or doesn’t explain again when woman seems unsure) Occasionally they find tiny spots where cells might have got out of the milk duct. Often that doesn’t mean anything different to what we’ve already got and it’s unlikely but sort of possible that they might find something else in the tissue that might change the pathology a bit. But I wouldn’t expect it because they’re [unclear: sounds like: tiny, microscopic.] Does that make

sense? (Mmm. So far.) Sort of? Um – what happens at this stage is that Breastscreen finds out about stuff for you and tells you what’s going on but it doesn’t actually treat anything.				
3	Invite questions: (don’t code if about treatment)			
i	specifically about the diagnosis eg how it differs from invasive breast cancer, natural history of DCIS	Eg yes	Eg 2P;	Eg 2P: Now is there anything else you want to ask me about the condition itself or what I’ve told you?
ii	in general	Eg yes	eg 6P;	Eg 6P: (at end of consultation): is there anything else you want to ask me or...

Other notes and examples of interest.....

Appendices Chapter 5

Appendix 5.1

De Morgan SE, Butow PN, Lobb EA, Price MA, Nehill C. Development and pilot testing of a communication aid to assist clinicians to communicate with women diagnosed with ductal carcinoma in situ (DCIS). Support Care Cancer 2011;19:717-723.

Development and pilot testing of a communication aid to assist clinicians to communicate with women diagnosed with ductal carcinoma in situ (DCIS)

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Abstract

Purpose The literature highlights the confusion amongst women diagnosed with ductal carcinoma in situ (DCIS) about aspects of their disease and treatment and the wide variation in how doctors communicate about DCIS. The DCIS communication aid (CA) was developed to assist clinicians to communicate with women diagnosed with DCIS and to improve women's understanding about their disease, prognosis and treatment options. This study aimed to assess patient and clinician perceptions of the CA.

Methods The CA included information and diagrams about key aspects of the diagnosis, prognosis, treatment and support. It was designed to be used in clinical consultations and taken home after the consultation. Australian women with DCIS ($n=18$) participated in structured interviews and clinicians ($n=7$), including surgeons and radiation oncologists, completed surveys to assess their perceptions of the CA. Main outcome measures included satisfaction with the content, design and diagrams in the CA, and perceptions of the benefits of the CA and its impact on doctor–patient communication.

Results All clinicians and women with DCIS reported that the CA would assist communication and help women understand their diagnosis.

Conclusions This is the first intervention designed to decrease the confusion amongst women with DCIS and improve doctor–patient communication in this area. This study highlights that interventions such as the DCIS communication aid may be a valuable resource for clinicians and women with DCIS. This study also highlights key communication challenges relating to DCIS.

Keywords Ductal carcinoma in situ (DCIS) · Communication aid · Doctor–patient communication · Knowledge · Patient-centred care · Treatment decision making

Introduction

Unlike invasive breast cancer, ductal carcinoma in situ (DCIS) cannot spread outside the milk ducts into other parts of the breast or to other parts of the body and a woman cannot die from DCIS alone [1]. The natural history of DCIS is not well understood. Laboratory and patient data suggest that some but not all cases of DCIS will progress to invasive breast cancer if left untreated [2]. However, it is currently not possible to accurately predict which women with DCIS will go on to develop invasive breast cancer [3]. This uncertainty complicates treatment decision making for patients and doctors [2, 4, 5].

Prevention of invasive breast cancer is considered the goal of treatment for DCIS. However, controversies exist in regards to the optimal management of DCIS with continuing debate about the use of radiotherapy in all DCIS patients, and

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the role of hormonal treatments and sentinel node biopsy [6–8]. Prognostic factors such as nuclear grade, tumour size, margin status, and age have been identified as important predictors of local recurrence [9]. Current research hopes to identify better prognostic markers leading to optimal individualised therapy with minimal overtreatment [1, 8].

The literature highlights the difficulties experienced by women diagnosed with DCIS in understanding whether DCIS is ‘cancer’ or not and whether it should be treated [4, 10–14]. A recent survey found that women’s confusion about their diagnosis was compounded by inadequate information about DCIS and conflicting descriptions about DCIS from health professionals [10]. The study also found that women who had poor knowledge about DCIS were more likely to worry about dying from DCIS, resulting in an unnecessary psychological burden for women with DCIS [10].

To date, there are no published studies about interventions designed to improve doctor–patient communication and patient understanding about DCIS. The literature demonstrates the benefits and feasibility of interventions that require direct physician involvement such as communication and decision aids used in consultations with patients [15, 16]. A communication aid presents evidence-based information in written, numerical and graphical formats [17, 18]. Unlike a decision aid, a communication aid is not designed to help people make specific and deliberative choices by presenting evidence on benefits and harms of the options, clarifying values, and guiding patients in the decision-making process [19]. Given that the primary goal of this study was to develop an intervention to improve women’s understanding about their diagnosis and treatment rather than to guide women in treatment decision making, a communication aid was considered to be the most appropriate intervention for this study.

The aims of this pilot study were to develop, evaluate and revise a DCIS communication aid (CA) for clinicians to use in their consultations with women diagnosed with DCIS.

Methods

Ethics approval was obtained from the Cancer Council Victoria, Human Research Ethics Committee and the University of Sydney, Human Research Ethics Committee.

Stage 1: Development of the CA

Given the lack of published guidelines for the development of communication aids, the consensus guidelines for developing and evaluating decision aids were used [20]. This involved identifying the need, feasibility and objectives for the communication aid (see above), and employing

a theoretical framework to guide its development and evaluation. The Ottawa Decision Support Framework used to guide the evaluation of decision aids [21] was adapted for a pilot study, to include: (a) assessing the determinants of patient knowledge and doctor–patient communication such as patient and clinician characteristics; and (b) evaluating the outcomes of the information support in terms of patients’ and clinicians’ perceptions of whether the CA would improve patient knowledge and doctor–patient communication.

The CA was designed as a colour booklet as this format has been shown to be acceptable and low cost.[17, 22]. The CA includes information and diagrams about key aspects of the diagnosis and treatment including: (1) what DCIS is and how DCIS differs from invasive breast cancer; (2) the natural history of DCIS and the uncertainty surrounding it; (3) the goal and importance of treatment and outline of treatment options; (4) the features of a woman’s DCIS which make her more or less likely to benefit from breast conserving surgery or mastectomy; (5) the features of a woman’s DCIS which make her more or less likely to develop invasive breast cancer; (6) the features of a woman’s DCIS which make her more or less likely to benefit from radiotherapy; (7) whether hormonal therapies are useful for women with DCIS and the potential side effects of hormonal therapies; (8) the risk of developing invasive breast cancer or DCIS after treatment; (9) follow-up after treatment; and (10) emotional support.

The risk communication literature highlights the importance of tailoring information to the individual [23]. The CA was designed to be personalised for the woman by the clinician marking key features of the women’s DCIS at relevant points, as highlighted in Fig. 1. A combination of visual (100 dot frequency diagrams), numerical (percentages and $n/100$) and word-based (low, medium and high) representations of risk were used as they have been shown to improve understanding of information [24]. Information about aspects of DCIS which increase the risk of developing invasive breast cancer, and which suggest a greater benefit from mastectomy or radiotherapy, were presented in weigh-scale diagrams, a format used in previous research [22].

A *How to Use* guide was developed for clinicians to assist them in using the CA in clinical consultations. The CA was not intended to be used like a script but rather to complement the clinicians’ usual communication style. Clinicians were instructed to use the diagrams and information where relevant during the consultation. Clinicians were also instructed to give the woman the CA at the end of the consultation to take home with her.

The information in the CA was based on a systematic review conducted by the authors summarising the evidence

a) The diagnosis of DCIS and how it differs from invasive breast cancer

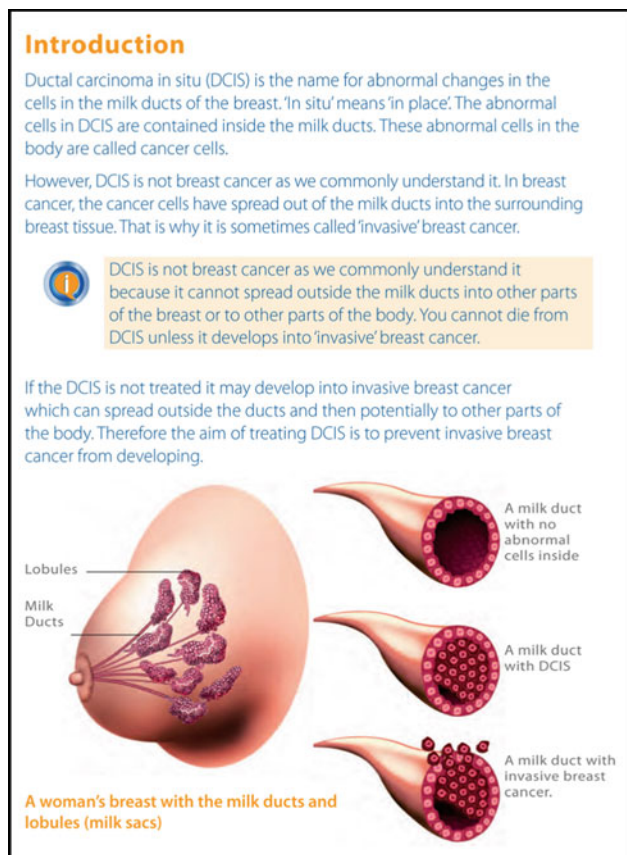
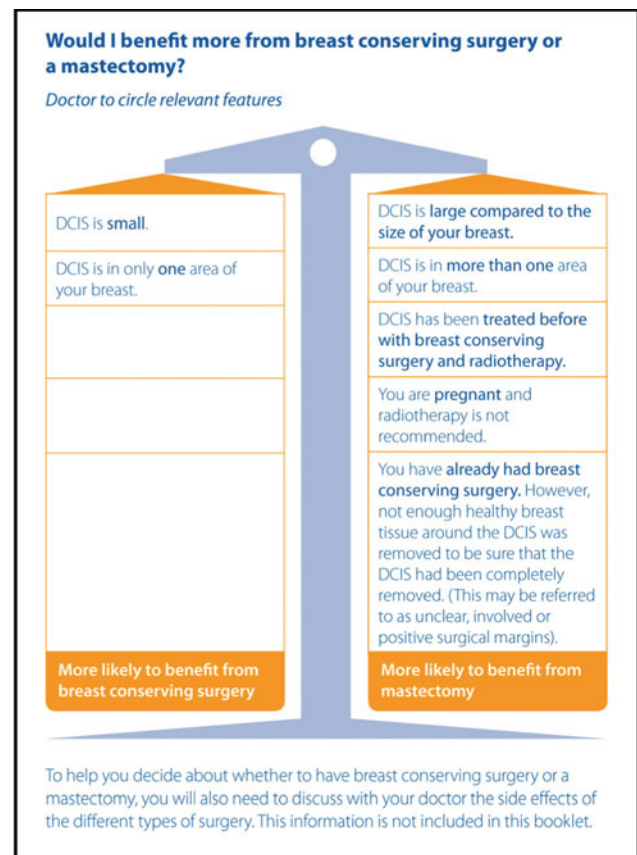


Fig. 1 Example of pages from the CA illustrating: **a** the diagnosis of DCIS and how it differs from invasive breast cancer. **b** Likelihood of benefiting more from breast conserving surgery or a mastectomy. **c**

b) Likelihood of benefiting more from breast conserving surgery or a mastectomy



The risk of developing invasive breast cancer or DCIS after treatment, *lower risk*. **d** The risk of developing invasive breast cancer or DCIS after treatment, *higher risk*

about women's experiences of being diagnosed and treated for DCIS. Electronic literature searches were performed using Medline, CINAHL and PsycINFO databases (1997–2007). Reference lists of identified papers and key authors were also manually searched for additional studies. Only published studies in the English language were considered for the review. Of the eleven studies included in the review, five were observational studies, including four cross-sectional studies and one longitudinal cohort study and six were qualitative studies. Key articles to support communication skills and the diagnosis and management of DCIS were also identified. The evidence was qualitatively synthesised by the authors into *Key DCIS Communication Elements*. The relevance, understandability and accuracy of the *Key DCIS Communication Elements* were reviewed by a multidisciplinary team composed of medical and radiation oncologists, a pathologist, a director of a mammographic screening service and senior health researchers specialising in cancer and doctor–patient communication.

Stage 2: Piloting the CA

Participants and procedure

Thirty women with DCIS diagnosed between September 2006 and August 2007 who had participated in an earlier study conducted by The Cancer Council Victoria and had expressed a willingness to be contacted about further research, were invited into this study. Women were purposively selected to represent a range of age, education and treatment categories. Women who provided written consent were mailed the CA and participated in telephone interviews. Interviews were audio-taped and transcribed. Interviews with 18 women were conducted, after which informational redundancy was reached and no further recruitment was undertaken [25].

Clinicians ($n=10$) actively treating women with DCIS were identified by the National Breast and Ovarian Cancer Centre (NBOCC) and invited to participate in the study. Clinicians ($n=7$) who provided written consent were given

c) The risk of developing invasive breast cancer or DCIS after treatment: *lower risk*

Lower risk

You may have a lower risk of developing invasive breast cancer or DCIS after treatment if you have:

Doctor to tick box for relevant features see page 10 for more details

☐ a small area of DCIS (less than approximately 1.5cm)


☐ DCIS is in only one area of your breast

☐ you have low grade DCIS

☐ you have clear and adequate surgical margins (greater than or equal to approximately 1cm)

☐ you have been diagnosed at an older age (greater than 60 years old).


What is the risk after breast conserving surgery **without** radiotherapy?²



100 women

The overall risk of developing invasive breast cancer or DCIS in the same breast is about 18%. In other words, about 18 women out of 100 women will develop invasive breast cancer or DCIS and 82 women won't develop invasive breast cancer or DCIS. About half of the problems that develop are due to invasive breast cancer.

What is the risk after breast conserving surgery **with** radiotherapy?²



100 women

The overall risk of developing invasive breast cancer or DCIS in the same breast is approximately 9%. In other words, approximately 9 women out of 100 women will develop invasive breast cancer or DCIS and 91 women won't develop invasive breast cancer or DCIS. About half of the problems that develop are due to invasive breast cancer.

d) The risk of developing invasive breast cancer or DCIS after treatment: *higher risk*

Higher risk

You may have a higher risk of developing invasive breast cancer or DCIS after treatment if you have:

Doctor to tick relevant features see page 10 for more details

☐ a larger area of DCIS (greater than approximately 4cm)


☐ DCIS is in more than one area of your breast

☐ you have high grade DCIS

☐ you have unclear or inadequate surgical margins (less than 1mm margin)

☐ you have been diagnosed at a younger age (less than 40 years old).


What is the risk after breast conserving surgery **without** radiotherapy?²



100 women

The overall risk of developing invasive breast cancer or DCIS in the same breast is about 35%. In other words, about 35 women out of 100 women will develop invasive breast cancer or DCIS and 65 women won't develop invasive breast cancer or DCIS. About half of the problems that develop are due to invasive breast cancer.

What is the risk after breast conserving surgery **with** radiotherapy?²



100 women

The overall risk of developing invasive breast cancer or DCIS in the same breast is approximately 19%. In other words, approximately 19 women out of 100 women will develop invasive breast cancer or DCIS and 81 women won't develop invasive breast cancer or DCIS. About half of the problems that develop are due to invasive breast cancer.

Fig. 1 (continued)

instructions about how to use the CA, asked to use the CA in two consultations, and completed a written survey.

Measures

A structured interview schedule to evaluate the CA was developed for the women with DCIS. Items included statements ($n=16$) with *disagree* or *agree* response options and open questions ($n=4$). The statements were framed positively and negatively to discourage automatic responses from participants. The interview assessed satisfaction with the content, diagrams and design of the CA, and perceived benefits and emotional impact of the CA. Suggestions for improvement were also elicited.

The structured interview schedule was adapted for clinicians and designed as a written survey. In addition to the issues explored with women, clinicians were asked about barriers and facilitators to using the CA, its impact on consultation length and style, and whether it would be appropriate for subgroups of women such as women with low education levels. Some open questions elicited

further feedback about the CA and suggestions for improvement.

Data analysis

Data were entered into the Statistical Package for Social Sciences (SPSS). Descriptive statistics were used to describe interview and survey responses. The qualitative data from open questions were coded into themes and sub-themes using thematic analysis [25].

Results

Piloting the CA with women diagnosed with DCIS

Sample

Participants ($n=18$) ranged from 42 to 84 years old (average, 63 years). Most participants were diagnosed 12 to 18 months prior to the study, and 61% had a post-school

qualification. All women had surgery (type of surgery not asked) and 44% had radiotherapy. All women spoke English as their first language.

Women's perceptions of the CA

Table 1 outlines women's perceptions of the benefits of the CA. All or most women felt the CA would help women to understand their diagnosis and treatment and would assist in communication between doctor and patient without increasing anxiety. Most women liked the content and format of the CA, including the diagrams.

"I found the whole guide very straightforward, very easy to understand and very helpful."

Women reported being confused and uninformed about how DCIS differs from invasive breast cancer and what would happen if the DCIS was left in the breast, and reflected on how the CA would assist in reducing confusion.

"It wasn't even pointed out to me the difference between invasive (breast cancer) and DCIS. So you're up in the air. If the doctors had this it would be very handy."

Most women liked that DCIS was described as "not breast cancer as we commonly understand it".

"DCIS is not breast cancer as we commonly understand it. A statement like that is really helpful. Because I wrestled with whether it was cancer or not."

Most women liked that DCIS was described as a risk of developing into breast cancer, except one woman who found this concept difficult to understand.

Some women felt the CA should contain more reassuring and positive information about the DCIS diagnosis.

Piloting the CA with clinicians in consultations with DCIS women

Sample

Five breast surgeons and two radiation oncologists from four major cities in Australia participated in the study. Four clinicians were female and three clinicians were male. Clinicians' experience in medical practice ranged from 10 to 22 years (average, 15 years). Clinicians consulted with, on average, five DCIS patients per month. Two clinicians used the CA during the initial diagnostic consultation at a mammographic screening service. Most clinicians ($n=5$) used the CA in subsequent consultations, either prior to or after the woman's surgery.

Clinicians' perceptions of the CA

Table 1 outlines clinicians' perceptions of the benefits of the CA. All or most clinicians felt the CA would help women to understand their diagnosis and treatment and assist them to communicate with women newly diagnosed with DCIS without increasing anxiety.

Table 1 Women's ($n=18$) and clinicians' ($n=7$) perceptions of the benefits of the CA

	Women's perceptions of the CA n (%)	Clinicians' perceptions of the CA n (%)
The DCIS diagnosis		
<i>The aid would help women to understand</i>		
Their diagnosis	18 (100%)	7 (100%)
The difference between DCIS and invasive breast cancer	17 (94%)	7 (100%)
The natural history of DCIS, that is, what will happen if the DCIS was left in the breast	15 (83%)	6 (86%)
Treatment for DCIS		
<i>The aid would help women to understand</i>		
Why treatment is recommended for DCIS	18 (100%)	6 (86%)
Their treatment options	18 (100%)	7 (100%)
Their prognosis after treatment, that is, how likely it is that the DCIS will come back or invasive breast cancer will develop after treatment	17 (94%)	6 (86%)
Communication with clinicians		
The aid would help women to communicate with their doctor about DCIS	18 (100%)	7 (100%)
Emotional impact of the CA		
The aid would not make women too anxious	17 (94%)	6 (86%)

Missing ($n=0$)

All of the clinicians said that they liked the content of the CA. Most clinicians used all of the information and diagrams in the CA in their order of publication. Most clinicians reported that they would use the CA regularly and most clinicians reported that they thought women with DCIS would like the CA. Most clinicians reported that the CA would not make their consultations too long or change their consultation style. One clinician thought that the CA would actually shorten consultations. A few clinicians reported that the CA was best used during consultations after surgery due to the amount and type of information included in the CA. For example, the features of the woman's DCIS used to determine risk recurrence were usually detected during surgery.

Most clinicians approved of DCIS being described as “not breast cancer as we commonly think of breast cancer”. Most clinicians also approved of DCIS being described as “a risk of developing into breast cancer”. However, one clinician thought that this description of DCIS was inappropriate and that DCIS should be re-conceptualised as a precursor to invasive breast cancer, a description that the clinician thought was more in keeping with current thinking about DCIS and its relationship to invasive breast cancer.

Most clinicians liked the format and diagrams in the CA.

“The Aid is visually powerful.”

However, there were mixed views about the risk diagrams in the CA. Some clinicians liked the risk diagrams, while others thought them too complex. Two clinicians thought that average risk statistics were not useful in discussions with women about risk of recurrence after treatment. Furthermore, most clinicians reported that the CA was not appropriate for women with only primary school education or for women from all cultural backgrounds.

Stage 3: Revision of the CA

The CA was revised based on the results of the evaluation with women and clinicians. The key changes to the CA included the following: (1) reassuring women that they cannot die from DCIS unless it develops into invasive breast cancer, and that treatment for DCIS is very successful; (2) conceptualising DCIS as a precursor to invasive breast cancer; (3) greater emphasis about the purpose of treatment; (4) introduction of risk categories for developing a recurrence; simplification of risk diagrams; and additional risk information; (5) space for clinicians to add contact details of local support groups. The *How to Use* guide for clinicians was revised to provide clearer instructions about using only the information and diagrams that were relevant in the particular consultation.

The revised CA is available on the National Breast and Ovarian Cancer Centre (NBOCC) website: www.nbocc.org.au

Discussion

The pilot testing of the CA revealed that both clinicians and women diagnosed with DCIS thought that the CA would help women to better communicate with their doctor about DCIS and to understand their diagnosis and treatment. This study also highlights the potential benefits of using visual aids with patients and shows the need for pilot testing of communication aids before being used in the intended setting or being tested in a randomised control trial.

Furthermore, this study highlights three key communication challenges relating to DCIS and suggests possible solutions. Firstly, communicating how DCIS differs from invasive breast cancer. This study suggests that it may be helpful to describe DCIS as “not breast cancer as we commonly understand it because it cannot spread...”. Secondly, communicating the natural history of DCIS. This study suggests that it may be helpful to communicate that “if the DCIS is not treated it may develop into invasive breast cancer which can spread...”. Thirdly, reassuring women with DCIS that they have a good prognosis. This study suggests that women may be reassured by statements such as “You cannot die from DCIS unless it develops into invasive breast cancer” and “DCIS can be treated successfully and most women diagnosed and treated for DCIS will not later develop invasive breast cancer”. There is a need for further research and consensus about how to effectively communicate the DCIS diagnosis to women.

This study was limited by the use of a small and select sample. Further research is required to formally evaluate the impact of the CA on communication in the consultation and patient outcomes, and the barriers to implementing the CA into routine practice. Given that most clinicians reported that the CA was not appropriate for women with low education and non-English-speaking backgrounds, there is a need to develop and evaluate adapted versions of the CA for these women.

Conclusions

This is the first communication aid developed for women diagnosed with DCIS. This study highlights that the DCIS Communication Aid is considered a valuable resource by clinicians and women. It is anticipated that the revised version of the CA will assist communication, promote better understanding about DCIS, and increase the well-being of women with DCIS.

The communication challenges highlighted in this study are not only relevant to DCIS but to all non-invasive cancers that are increasingly being detected with the escalation of screening.

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Conflicts of interest None.

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Appendix 5.2

DCIS Communication Aid (CA): Understanding ductal carcinoma in situ (DCIS) and deciding about treatment. National Breast and Ovarian Cancer Centre (NBOCC) 2009 ISBN Print: 978 1 74127 149 2 Available online at Cancer Australia: www.canceraustralia.gov.au



Understanding ductal carcinoma in situ (DCIS) and deciding about treatment

Developed by National Breast and Ovarian Cancer Centre

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We gratefully acknowledge the support of the many women and health care professionals who provided valuable input into development of this resource.

How to use this resource

Understanding ductal carcinoma in situ communication aid is designed to assist clinicians to communicate with women diagnosed with DCIS to improve their understanding about their diagnosis, prognosis, treatment and support.

The aid is designed to be used with the woman during the consultation then given to the woman to take home as an information resource. **This aid is not designed to be a stand alone information resource for women.**

The order in which you use the diagrams and information will depend on whether you are using the aid in the initial diagnostic consultation, in a pre-operative consultation or a post-operative consultation. **You do not need to use every page of the aid and you do not need to use all diagrams and information on the pages that you use in the aid.**

You may **circle** the relevant features of the woman's DCIS in the diagrams of weighing scales on pages 9, 10 & 11 if you find this useful.

You may **circle** the woman's risk category for recurrence: lower, intermediate and higher risk; and **tick the boxes** for relevant features associated with lower and higher risk on pages 13, 14 & 15 if you find this useful.

Introduction

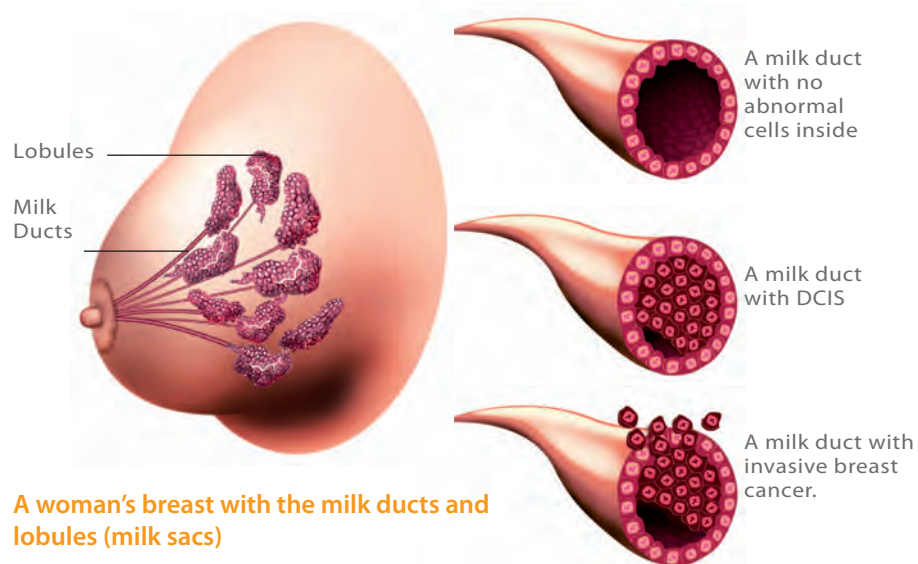
Ductal carcinoma in situ (DCIS) is the name for abnormal changes in the cells in the milk ducts of the breast. 'In situ' means 'in place'. The abnormal cells in DCIS are contained inside the milk ducts. These abnormal cells in the body are called cancer cells.

However, DCIS is not breast cancer as we commonly understand it. In breast cancer, the cancer cells have spread out of the milk ducts into the surrounding breast tissue. That is why it is sometimes called 'invasive' breast cancer.



DCIS is not breast cancer as we commonly understand it because it cannot spread outside the milk ducts into other parts of the breast or to other parts of the body. You cannot die from DCIS unless it develops into 'invasive' breast cancer.

If the DCIS is not treated it may develop into invasive breast cancer which can spread outside the ducts and then potentially to other parts of the body. Therefore the aim of treating DCIS is to prevent invasive breast cancer from developing.



A woman's breast with the milk ducts and lobules (milk sacs)

Why do I need treatment for DCIS?

It is not reliably known the percentage of women with DCIS who would develop invasive breast cancer if they were not treated.

Also, it is not possible to predict which women with DCIS will develop invasive breast cancer if they were not treated or how long after the diagnosis of DCIS an invasive breast cancer would develop. In other words, some women with DCIS may never develop any problems if they are not treated. However, some women with DCIS may develop invasive breast cancer.

Current research aims to help health professionals better predict which women with DCIS will develop invasive breast cancer and how long after the diagnosis of DCIS this would occur.

Because DCIS may develop into invasive breast cancer and invasive breast cancer can spread and cause death, **all women with DCIS are recommended to have treatment.** Treatment for DCIS aims to help prevent invasive breast cancer from developing and DCIS from coming back in the breast.



DCIS can be treated successfully and most women diagnosed and treated for DCIS will not later develop invasive breast cancer.

Treatment for DCIS

Treatment for DCIS may involve:

1. Surgery

Treatment for DCIS usually involves surgery. The goal of surgery is to remove the area of DCIS. Surgery involves either breast conserving surgery (lumpectomy) or a mastectomy. See page 7 for more details.

2. Radiotherapy

Treatment after breast conserving surgery usually involves radiotherapy. The goal of radiotherapy is to destroy any abnormal cells that may be left in the breast after surgery. Radiotherapy is not recommended after a mastectomy because the risk of developing invasive breast cancer is very small. See page 114 for more details.

3. Hormonal treatments

Hormonal treatments, for example, Tamoxifen, **may be considered** for women with DCIS after surgery. Hormonal treatments may decrease the risk of developing invasive breast cancer in both breasts. This is an area of current research. The benefits of hormonal treatments need to be weighed against the side effects for each woman's particular situation. Talk to your doctor to see if this is an option for you.

Chemotherapy is not useful in the treatment of women with DCIS because the abnormal cells have not spread out of the milk ducts.

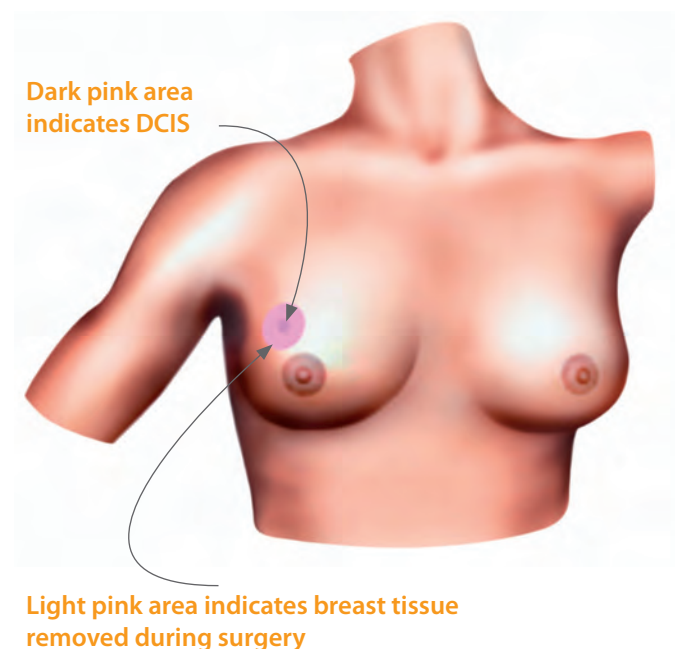


It is important to be informed before you make a decision about treatment. Take some time to find out about the treatment options and what the best course is for you.

Surgery

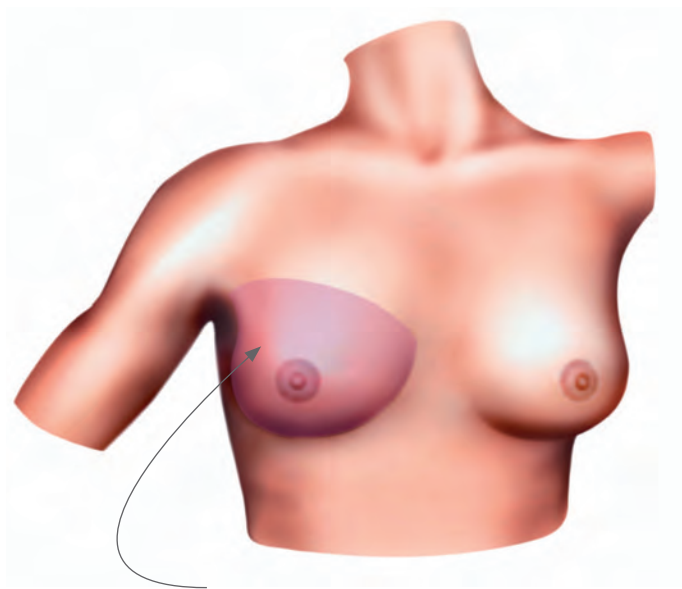
Option 1: Breast conserving surgery

Most women with DCIS are treated with breast conserving surgery with radiotherapy. **Breast conserving surgery** means that a woman's whole breast is **not** removed. Breast conserving surgery removes the area of DCIS plus a small area of healthy breast tissue around the DCIS (called the 'surgical margin'). Breast conserving surgery is sometimes also called a **lumpectomy**. Usually lymph nodes under the armpits, which drain fluid from the breasts, do not need to be removed as DCIS does not spread outside the breasts.



Option 2: Mastectomy

Mastectomy means surgery to remove a woman's whole breast, including the nipple. Usually lymph nodes under the armpits, which drain fluid from the breasts, do not need to be removed as DCIS does not spread outside the breasts. **Breast reconstruction** (at the time of the mastectomy or some time later) is almost always an option. Women not wanting to have breast reconstruction can wear a **prosthesis** (a breast form that can be removed and is worn under clothes to give a natural looking shape).



Pink area indicates breast tissue removed during surgery

Would I benefit more from breast conserving surgery or a mastectomy?

Doctor to circle relevant features

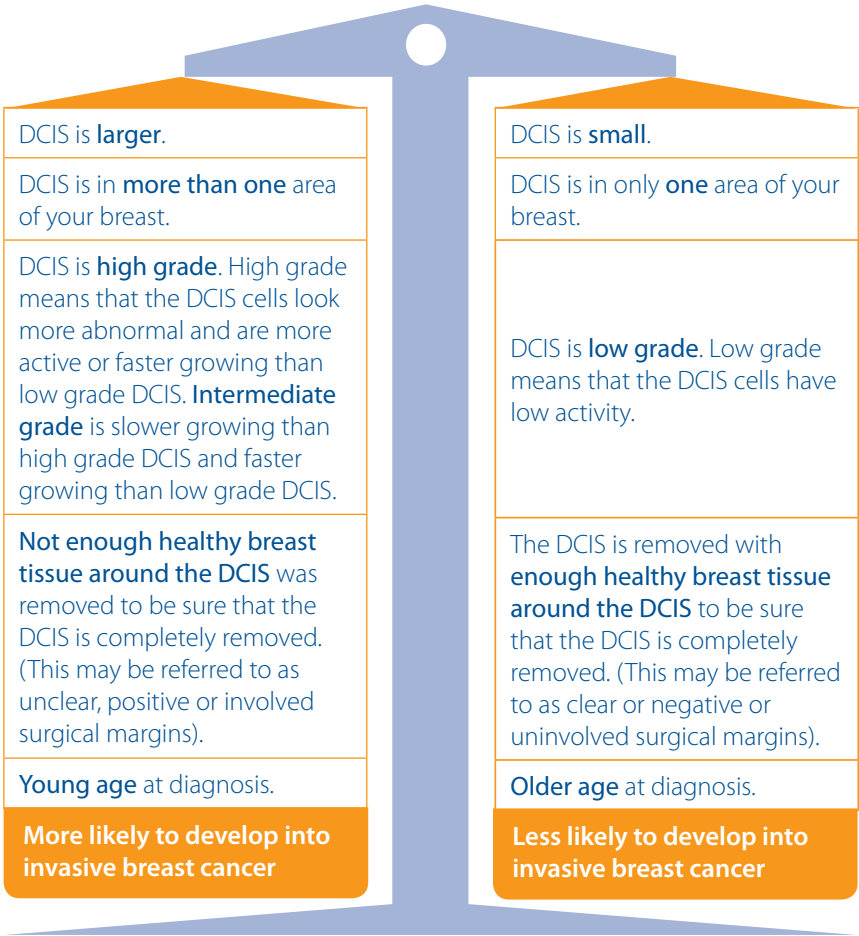
DCIS is small .	DCIS is large compared to the size of your breast.
DCIS is in only one area of your breast.	DCIS is in more than one area of your breast.
	DCIS has been treated before with breast conserving surgery and radiotherapy .
	You are pregnant and radiotherapy is not recommended.
	You have already had breast conserving surgery . However, not enough healthy breast tissue around the DCIS was removed to be sure that the DCIS had been completely removed. (This may be referred to as unclear, involved or positive surgical margins).
More likely to benefit from breast conserving surgery	More likely to benefit from mastectomy

To help you decide about whether to have breast conserving surgery or a mastectomy, you will also need to discuss with your doctor the side effects of the different types of surgery. This information is not included in this booklet.

What features of your DCIS make it more or less likely to develop into invasive breast cancer?

Your pathology report after a breast biopsy and after surgery will tell you and your doctor the features of your DCIS. Even if you have all the features listed on the left, you may never develop invasive breast cancer.

Doctor to circle relevant features



Radiotherapy

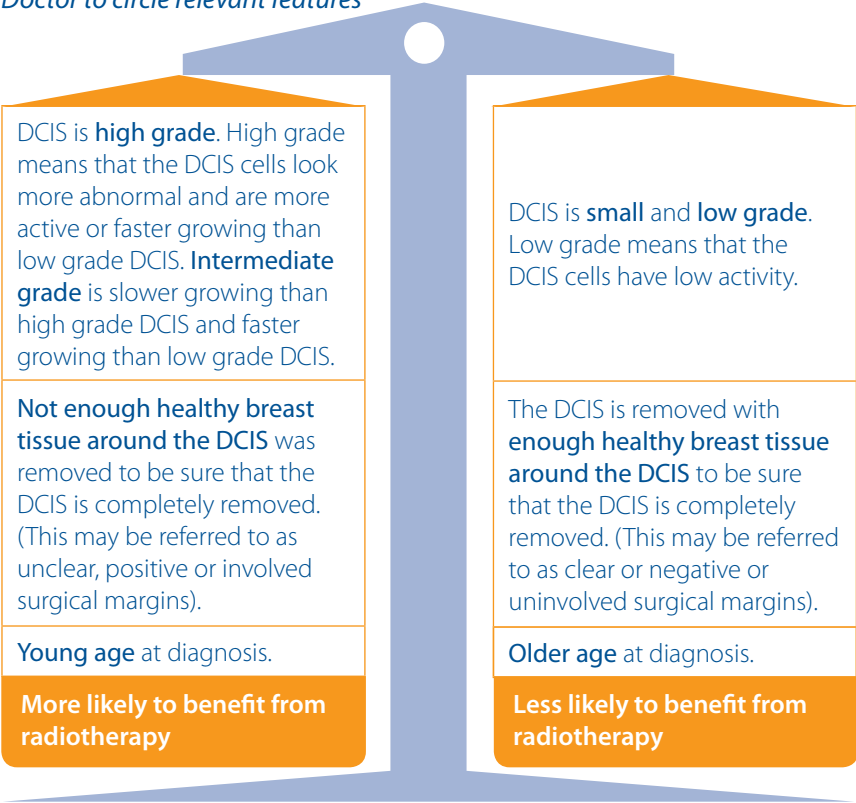
Radiotherapy is often recommended after breast conserving surgery. Radiotherapy is not needed after a mastectomy. Radiotherapy uses X-rays (low doses of radiation) to destroy any abnormal cells that may be left in a woman's breast after surgery.



Radiotherapy decreases the risk of developing invasive breast cancer and DCIS again by at least half.

Would I benefit from radiotherapy?

Doctor to circle relevant features



To help you decide about whether to have radiotherapy, you will also need to discuss with your doctor the side effects of radiotherapy. This information is not included in this booklet.

What is the risk of developing invasive breast cancer or DCIS after treatment?

Your risk of developing invasive breast cancer or DCIS after treatment¹ is a: *Doctor to circle risk category:*

- **lower risk**
- **intermediate risk**
- **higher risk**

If you are at lower risk see page 13. If you are at higher risk see page 14 and 15. If you are at intermediate risk your risk is between lower and higher risk.

Your doctor may not know all the features of your DCIS if you have not yet had surgery. After surgery your doctor will be better able to determine your risk.

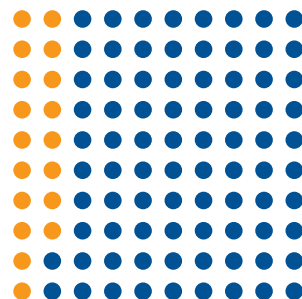
Lower risk

You may have a lower risk of developing invasive breast cancer or DCIS after treatment if you have:

Doctor to tick box for relevant features see page 10 for more details

- ☐ a small area of DCIS (less than approximately 1.5cm)
- ☐ DCIS is in only one area of your breast
- ☐ you have low grade DCIS
- ☐ you have clear and adequate surgical margins (greater than or equal to approximately 1 cm)
- ☐ you have been diagnosed at an older age (greater than 60 years old).

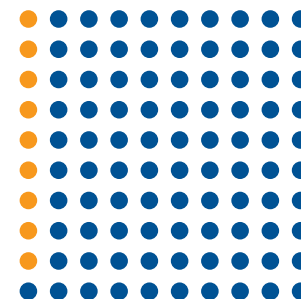
What is the risk after breast conserving surgery **without** radiotherapy?²



100 women

The overall risk of developing **invasive breast cancer or DCIS** in the same breast is about 18%. In other words, about 18 women out of 100 women will develop invasive breast cancer or DCIS and 82 women won't develop invasive breast cancer or DCIS. About half of the problems that develop are due to invasive breast cancer.

What is the risk after breast conserving surgery **with** radiotherapy?²



100 women

The overall risk of developing **invasive breast cancer or DCIS** in the same breast is approximately 9%. In other words, approximately 9 women out of 100 women will develop invasive breast cancer or DCIS and 91 women won't develop invasive breast cancer or DCIS. About half of the problems that develop are due to invasive breast cancer.

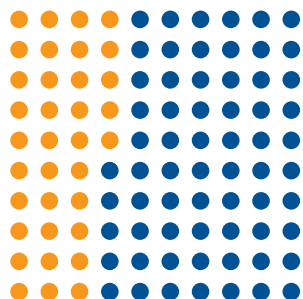
Higher risk

You may have a higher risk of developing invasive breast cancer or DCIS after treatment if you have:

Doctor to tick relevant features see page 10 for more details

- ☐ a larger area of DCIS (greater than approximately 4cm)
- ☐ DCIS is in more than one area of your breast
- ☐ you have high grade DCIS
- ☐ you have unclear or inadequate surgical margins (less than 1mm margin)
- ☐ you have been diagnosed at a younger age (less than 40 years old).

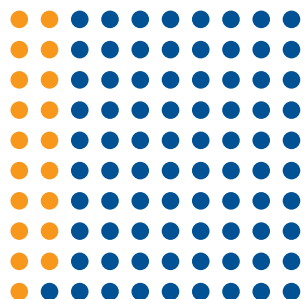
What is the risk after breast conserving surgery **without** radiotherapy?²



100 women

The overall risk of developing **invasive breast cancer** or **DCIS** in the same breast is about 35%. In other words, about 35 women out of 100 women will develop invasive breast cancer or DCIS and 65 women won't develop invasive breast cancer or DCIS. About half of the problems that develop are due to invasive breast cancer.

What is the risk after breast conserving surgery **with** radiotherapy?²

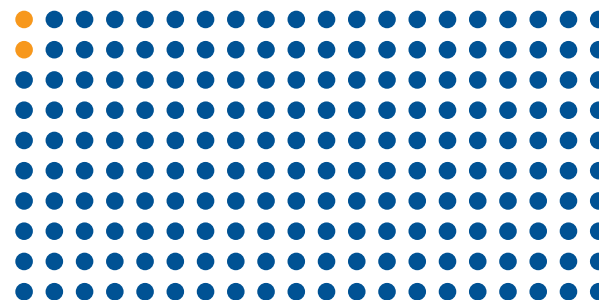


100 women

The overall risk of developing **invasive breast cancer** or **DCIS** in the same breast is approximately 19%. In other words, approximately 19 women out of 100 women will develop invasive breast cancer or DCIS and 81 women won't develop invasive breast cancer or DCIS. About half of the problems that develop are due to invasive breast cancer.

What is the risk after a mastectomy?³

There is still a very small risk of developing DCIS or invasive breast cancer in the small amount of breast tissue left after a mastectomy.



200 women

After a mastectomy for DCIS: (figures include lower and higher risk)

The risk of developing **invasive breast cancer** in the small breast tissue that is left is less than 1% and your risk of developing **DCIS** is less than 1%. In other words, after mastectomy, 1 woman out of 200 women will develop invasive breast cancer and 1 woman out of 200 women will develop DCIS

What is the risk of developing invasive breast cancer in the general population in Australia?

If all Australian women lived to the age of 85 years, then one in 8 women would develop **invasive breast cancer** during their lifetime. This includes women who have been diagnosed with DCIS and women who have not been diagnosed with DCIS. In other words, approximately 13 women out of 100 women will develop invasive breast cancer during their lifetime, if all women lived to the age of 85 years.

Women who have been diagnosed with DCIS have an increased risk of subsequently developing breast cancer compared to women in the general population.

What follow-up will I need?

Your surgeon, radiation oncologist, medical oncologist and/or GP will do regular check-ups of your breast and discuss the side effects of any treatments you have had. Regular check-ups involves mammograms each year and regular physical examination of your breasts for abnormal lumps.



Regular check-ups means finding any abnormal changes in your breasts and treating them early.

How can I get more emotional support?

It is common for women to feel shocked, anxious, depressed or have concerns after a diagnosis of DCIS. Coping with the uncertainty about whether you may develop invasive breast cancer or whether the DCIS may come back, and coping with treatments, can be difficult.

Sharing your thoughts and feelings with your family and friends, your GP, your surgeon, your breast care nurse or a counselor/psychologist can help you cope with your diagnosis.



Help is available if you need it. You don't have to cope alone. Don't put up with any feelings that you feel overwhelmed by.

Ask your GP to refer you to a breast nurse, counsellor, psychologist or psychiatrist if you feel you would benefit from more support.

You may also call the **Cancer Council Helpline** on **13 20 11** for more information and support. Staff on the Cancer Council Helpline can talk with you confidentially about your feelings and concerns and may be able to refer you to a support group in your area.

Support groups hold regular meetings for people in similar circumstances to talk about their experiences and to share their concerns. There may be support groups for women with DCIS in your area. If not, there are many support groups for women with invasive breast cancer. These women will have similar treatments to you (apart from some women with invasive breast cancer who will have chemotherapy).

Support may also be available from *(doctor to insert if appropriate)*:

Phone number: _____

References

1. Silverstein MJ. The University of California/Van Nuys prognostic index for ductal carcinoma in situ of the breast. *Am. J. Surg.* 2003; 186(4):337-43.
2. Bijker N, Meijnen P, Johannes LP, et al. Breast-conserving treatment with or without radiotherapy in ductal carcinoma in situ: ten-year results of European Organisation for Research and Treatment of Cancer randomized phase III trial 10853 – a study by the EORTC Breast Cancer Cooperative Group and EORTC Radiotherapy Group. *J. Clin. Oncol.* 2006; 24(21):3381-87.
3. Boyages J, Delaney G and Taylor R. Predictors of Local Recurrence after Treatment of Ductal Carcinoma In Situ: A Meta-Analysis. *Cancer.* 1999. 85:616-28.

This image shows a full page of white paper with horizontal blue dashed lines. The lines are evenly spaced and run across the width of the page, providing a guide for handwriting practice. There are no margins, text, or other markings on the page.

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Appendix 5.3

How to use the DCIS Communication Aid (CA)

Understanding ductal carcinoma in situ (DCIS) and deciding about treatment

The National Breast and Ovarian Cancer Centre (NBOCC) developed the CA to assist clinicians in communicating the diagnosis and treatment of DCIS. The CA functions as a visual and information aid for clinicians to use during their consultations and a booklet for women to take home.

Step 1

- Familiarise yourself with the content and diagrams on each page of the CA.

Step 2

- During the consultation use the diagrams and information where relevant and in any order. The diagrams and information that you find useful in the CA will depend on whether you are using the CA during the initial diagnostic consultation or in subsequent consultations, either prior to or after the woman's surgery. You do not need to use all the diagrams and information in the CA. The CA is intended to be an adjunct to your consultation. It is not intended to be a script, but rather to complement your usual communication style.
- You may tailor the information in the CA to the patient by a) **circling** the relevant features of the woman's DCIS in the diagrams of weighing scales on *Pages 9-11*; b) **circling** the woman's risk category for recurrence: lower, intermediate and higher risk on *Page 12*; and c) **ticking the boxes** for relevant features associated with lower and higher risk on *Pages 13-15*.

Step 3

- Give the CA to women at the end of the consultation to take home with her.

Table 1: Information and diagrams included in the DCIS Communication Aid (CA)

Information	Diagrams	Page
<i>Acknowledgments</i>		2
<i>How to use this resource</i>		3
1 What DCIS is and how DCIS differs from invasive breast cancer	<i>Diagrams of DCIS and invasive breast cancer in the breast; and in the milk duct (detail)</i>	4
2 The natural history of DCIS and the uncertainty surrounding it	<i>None</i>	5
3 The goal and importance of treatment and outline of treatment options	<i>Diagrams of breast conserving surgery and a mastectomy</i>	5-8
4 The features of a woman's DCIS which make her more or less likely to benefit from breast conserving surgery or mastectomy	<i>Weigh scale diagram</i>	9
5 The features of a woman's DCIS which make her more or less likely to develop invasive breast cancer	<i>Weigh scale diagram</i>	10
6 The features of a woman's DCIS which make her more or less likely to benefit from radiotherapy	<i>Weigh scale diagram</i>	11
7 The risk of developing invasive breast cancer or DCIS after treatment (breast conserving surgery with or without radiotherapy for low and high risk groups; a mastectomy)	<i>100 dot diagrams</i>	12-15
8 The risk of developing invasive breast cancer in the general population	<i>None</i>	16
9 Follow-up after treatment	<i>None</i>	17
10 The impact of a diagnosis of DCIS and where women with DCIS can get additional emotional support	<i>None</i>	18

Appendix 5.4

Dear

Thank you for participating in the study *Women's experiences of being diagnosed and treated for ductal carcinoma in situ of the breast* which involved an interview about your experiences of being diagnosed and treated for DCIS. At the end of this interview you said that you were willing to be sent information about another smaller study about DCIS.

This study is being conducted as part of a PhD thesis by Ms Simone De Morgan, University of Newcastle. Professor Phyllis Butow, A/Prof Elizabeth Lobb, Dr Melanie Price and Jillian McDonald from the Medical Psychology Research Unit, School of Psychology, University of Sydney are also part of the research team. The project has been funded by the National Breast and Ovarian Cancer Centre.

The research team have developed an information booklet (called a DCIS Communication Aid) for women with ductal carcinoma in situ (DCIS). The DCIS Communication Aid aims to make it easier for women with DCIS to understand their diagnosis and treatment and to discuss these issues with their doctor. In this study, the research team are seeking feedback from women who have already been treated for DCIS, about how useful they think this booklet will be, before it is given to women newly diagnosed with DCIS. An information sheet about the study is enclosed.

If you wish to participate please complete the enclosed consent form by the (*insert date two weeks from mail*) with your contact details and return it in the reply paid envelope to the Medical Psychology Research Unit, School of Psychology, University of Sydney.

If you do not wish to participate then **do not return** the consent form and your contact details will not be released and you will not be contacted again about this study.

The information you provide will be kept secure and confidential. Published reports about the findings from the study will only contain group results, so no individual will be identified in these reports. If you decide to participate in the study, you are free to withdraw at a later date.

Thank you for considering this request. Your time and assistance is appreciated.

Yours sincerely

Appendix 5.5

RESEARCH STUDY EVALUATING THE USEFULNESS OF THE DCIS COMMUNICATION AID FOR WOMEN

Information sheet for women

You are invited to take part in a research study evaluating the usefulness of a communication aid for women with ductal carcinoma in situ (DCIS). Recent research suggests that women with DCIS are frequently confused about their diagnosis. The DCIS Communication Aid aims to make it easier for women with DCIS to understand their diagnosis and treatment and to discuss these issues with their doctor. In this study we seek to get feedback from women who have already been treated for DCIS, about how useful they think this aid will be, before we give it to women newly diagnosed with DCIS.

The study is being conducted as part of a PhD thesis by Ms Simone De Morgan, University of Newcastle. Professor Phyllis Butow, A/Prof Elizabeth Lobb, Dr Melanie Price and Jillian McDonald from the Medical Psychology Research Unit, School of Psychology, University of Sydney are also part of the research team. The project has been funded by the National Breast and Ovarian Cancer Centre.

If you agree to participate in this study, you will be asked to read the aid and be interviewed by telephone about how useful you think the aid would be, and any changes you would recommend. The phone interview will be audio-taped so that we are able to record all your comments. We expect that it will take you about 10 minutes to read the aid, and that the interview will take about 15 minutes.

All aspects of the study, including results, will be strictly confidential and only the investigators named above will have access to information about participants. A report of the study may be submitted for publication, but individual participants will not be identifiable in such a report.

Participation in this study is entirely voluntary: you are not obliged to participate and - if you do participate - you can withdraw at any time. Whatever your decision, it will not affect your medical treatment or your relationship with medical staff.

Please feel free to contact Jillian McDonald or Simone De Morgan on (02) 9036 5289 if you have any questions about this project.

If you have any questions or concerns about your diagnosis or treatment after participating in the interview please contact your treatment team who will best be able to answer your questions.

<p>Any person with concerns or complaints about the conduct of a research study can contact the Senior Ethics Officer, Ethics Administration, University of Sydney on (02) 9351 4811 (Telephone); (02) 9351 6706 (Facsimile) or gbriody@usyd.edu.au (Email).</p>
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RESEARCH STUDY EVALUATING THE USEFULNESS OF A COMMUNICATION AID FOR WOMEN WITH DCIS

Information sheet for clinicians

You are invited to take part in a research study evaluating the usefulness of a communication aid for women with ductal carcinoma in situ (DCIS). Recent research suggests that women with DCIS are frequently confused about their diagnosis. The DCIS Communication Aid aims to make it easier for women with DCIS to understand their diagnosis and treatment and to discuss these issues with their doctor. We would like to receive your feedback about the aid and whether you think that the aid would be useful during consultations with women with DCIS.

The study is being conducted as part of a PhD thesis by Ms Simone De Morgan, University of Newcastle. Professor Phyllis Butow, A/Prof Elizabeth Lobb, Dr Melanie Price and Jillian McDonald from the Medical Psychology Research Unit, School of Psychology, University of Sydney are also part of the research team. The project has been funded by the National Breast and Ovarian Cancer Centre.

You are being contacted about this study, because you have worked with the National Breast and Ovarian Cancer Centre. If you agree to participate in this study, you will be asked to use the aid in two consultations with women with DCIS, and then complete a 3 page questionnaire asking for your views on the aid, barriers to its use and any changes you would recommend. We have enclosed a stamped addressed envelope in which to return the questionnaire. We expect that the questionnaire will take about 10 minutes to complete.

All aspects of the study, including results, will be strictly confidential and only the investigators named above will have access to information on participants. A report of the study may be submitted for publication, but individual participants will not be identifiable in such a report.

Participation in this study is entirely voluntary: you are not obliged to participate and - if you do participate - you can withdraw at any time.

Please feel free to contact Jillian McDonald or Simone De Morgan on (02) 9036 5289 if you have any questions about this project.

Any person with concerns or complaints about the conduct of a research study can contact the Senior Ethics Officer, Ethics Administration, University of Sydney on (02) 9351 4811 (Telephone); (02) 9351 6706 (Facsimile) or gbriody@usyd.edu.au (Email).

Appendix 5.6

Women's Consent Form

RESEARCH STUDY EVALUATING THE USEFULNESS OF THE DCIS COMMUNICATION AID FOR WOMEN

I,
[name]

have read and understood the information for participants on the above named research study and have discussed it with the researcher/s.

I am aware that I will be asked to read a DCIS communication aid and provide feedback to the researcher over the phone. I am aware that the communication aid may contain information new to me which may raise questions or concerns.

I freely choose to participate in this study and understand that I can withdraw without compromise at any time.

I also understand that the research study is strictly confidential.

I hereby agree to participate in this research study.

Signature:

Name:

Address:

Phone number: Hm.....Mobile.....Other.....

Preferred day to be contacted to book an interview time : Tues / Wed (Pls circle)*

Date:

*Please note: this is a brief phone call to arrange an interview time that is convenient for you

Please return this consent form in the reply paid envelope provided

Appendix 5.7

RESEARCH STUDY EVALUATING THE USEFULNESS OF THE DCIS COMMUNICATION AID

Women diagnosed with DCIS

Interview schedule

Thank you very much for taking the time to talk with me today. Are you still happy to have this conversation recorded?

Date of interview _____

Demographics

1. Can you tell me your age? _____
2. When were you diagnosed with DCIS? -----/----- (month / year)
3. What treatment did you have for your DCIS? (tick more than one)
 - ☐ Surgery
 - ☐ Chemotherapy
 - ☐ Radiotherapy
 - ☐ Hormone therapy
4. Is English your first language?
 - ☐ Yes
 - ☐ No
5. Which of the following best describes your highest education level?
 - ☐ Primary school only
 - ☐ Some secondary school
 - ☐ School Certificate /Year 10 / 4th form / Intermediate certificate
 - ☐ HSC / Year 12 / 6th form / Leaving Certificate
 - ☐ College (Diploma or Certificate) eg TAFE, business college
 - ☐ University (Degree)

The DCIS Communication Aid

Can you tell me whether you disagree or agree with the following statements.

		Disagree	Agree
1	The aid would help women to understand their diagnosis	<input type="checkbox"/> ¹	<input type="checkbox"/> ²
2	The aid would help women to understand the difference between DCIS and invasive breast cancer	<input type="checkbox"/> ¹	<input type="checkbox"/> ²

		Disagree	Agree
3	The aid would help women to understand the natural history of DCIS, that is, what will happen if the DCIS was left in the breast	<input type="checkbox"/> ¹	<input type="checkbox"/> ²
4	The aid would help women to understand their prognosis after treatment, that is, how likely it is that the DCIS will come back or invasive breast cancer will develop after treatment	<input type="checkbox"/> ¹	<input type="checkbox"/> ²
5	The aid would help women to understand why treatment is recommended for DCIS	<input type="checkbox"/> ¹	<input type="checkbox"/> ²
6	The aid would help women to understand their treatment options	<input type="checkbox"/> ¹	<input type="checkbox"/> ²
7	This aid would make women too anxious	<input type="checkbox"/> ¹	<input type="checkbox"/> ²
8	I like that DCIS is described in this aid as <u>not</u> breast cancer as we commonly think of breast cancer	<input type="checkbox"/> ¹	<input type="checkbox"/> ²
9	I like that DCIS is described in this aid as a risk of developing into breast cancer	<input type="checkbox"/> ¹	<input type="checkbox"/> ²
10	Overall, I like the content of the aid	<input type="checkbox"/> ¹	<input type="checkbox"/> ²
11	Overall, I <u>dislike</u> the format of the aid	<input type="checkbox"/> ¹	<input type="checkbox"/> ²
12	This aid would help women to communicate with their doctor about DCIS	<input type="checkbox"/> ¹	<input type="checkbox"/> ²

Diagrams

		Disagree	Agree
1	I like the diagrams of DCIS and invasive breast cancer in the breast on Page 1 of the aid	<input type="checkbox"/> ¹	<input type="checkbox"/> ²
2	I like the diagrams of breast conserving surgery and mastectomy on Page 3 of the aid	<input type="checkbox"/> ¹	<input type="checkbox"/> ²
3	I like the diagrams of weighing scales on Page 4, 5 & 6 of the aid	<input type="checkbox"/> ¹	<input type="checkbox"/> ²
4	I like the risk diagrams on Page 7, 8 & 9 of the aid	<input type="checkbox"/> ¹	<input type="checkbox"/> ²

Are there any comments you would like to make about the diagrams in the aid?

Is there anything that you felt confused about or did not understand in the aid? (Note page number and paragraph)

Are there any other changes you would like to make to the aid? (Note page number and paragraph)

Is there anything else you would like to say about the aid?

THANK YOU FOR HELPING US WITH THIS STUDY!
WOULD YOU LIKE A SUMMARY OF THE STUDY RESULTS?
Yes / No

Appendix 5.8

Dear

Re: Research Study evaluating the usefulness of a communication aid for women with ductal carcinoma in situ (DCIS)

You are invited to take part in a research study evaluating the usefulness of a communication aid for women with ductal carcinoma in situ (DCIS). Recent research suggests that women with DCIS are frequently confused about their diagnosis. The DCIS Communication Aid aims to make it easier for women with DCIS to understand their diagnosis and treatment and to discuss these issues with their doctor. We would like your feedback about the aid and whether you think that the aid would be useful during consultations with women with DCIS.

The study is being conducted as part of a PhD thesis by Ms Simone De Morgan, University of Newcastle. Professor Phyllis Butow, A/Prof Elizabeth Lobb, Dr Melanie Price and Jillian McDonald from the Medical Psychology Research Unit, School of Psychology, University of Sydney are also part of the research team. The project has been funded by the National Breast and Ovarian Cancer Centre.

Please find enclosed an information package which includes:

- An information sheet for clinicians
- A Consent Form
- Three copies of the DCIS Communication Aid (one for each patient and one to keep for your own reference)
- The DCIS Communication Aid "How to use" guide
- A survey
- Two reply paid envelopes – one for the consent form and one for the survey

If you wish to participate in the study, please complete and sign the consent form and return it in the envelope provided.

Before using the aid with two patients, it is a requirement of the study that you are given standardised instructions on using it. I will therefore be in touch with you shortly to book a time to go over these issues with you.

If you have any questions, please do not hesitate to contact me or Ms Simone De Morgan on 9036 5289.

Yours sincerely

Jillian MacDonald
Research Officer
Medical Psychology Research Unit

Appendix 5.9

CONSENT FORM (CLINICIANS)

RESEARCH STUDY EVALUATING THE USEFULNESS OF THE DCIS COMMUNICATION AID FOR WOMEN

I,
[name]

have read and understood the information for participants on the above named research study and have discussed it with the researcher/s.

I am aware that I will be asked to use a communication aid about DCIS in two consecutive consultations with women with DCIS, and complete a short 3 page questionnaire about its utility.

I freely choose to participate in this study and understand that I can withdraw without compromise at any time.

I also understand that the research study is strictly confidential.

I hereby agree to participate in this research study.

Signature:

Name:

Date:

Appendix 5.10

RESEARCH STUDY EVALUATING THE USEFULNESS OF THE DCIS COMMUNICATION AID

Clinicians

Thank you very much for taking the time to complete this questionnaire. Please answer all questions as indicated below. At the end of the questionnaire there is space where you can make additional comments if you wish.

When you have completed the questionnaire, please return it to Jillian MacDonald, either by mailing it in the attached reply-paid envelope or by faxing it to +61-2-9036-5292.

Demographics

4. What is your medical speciality?
☐¹ Breast Surgeon
☐² Medical Oncologist
☐³ Radiation Oncologist
5. What type of service do you practice in? (you may tick more than one)
☐¹ Public hospital
☐² Private hospital
6. What is your gender
☐¹ Male
☐² Female
7. How many years have you been in clinical practice?
8. How many women with DCIS do you see, on average, each month?
.....
9. In what type of consultation did you use the aid ? *(please tick one or more boxes)*
☐¹ initial diagnostic consultation(s)
☐² post diagnostic consultation(s) outside BreastScreen

The DCIS Communication Aid

Please indicate whether you disagree or agree with the following statements.

		Disagree	Agree
1	The aid would help women to understand their diagnosis	<input type="checkbox"/> ¹	<input type="checkbox"/> ²
2	The aid would help women to understand the difference between DCIS and invasive breast cancer	<input type="checkbox"/> ¹	<input type="checkbox"/> ²
3	The aid would help women to understand the natural history of DCIS, including the uncertainty of the prognosis of DCIS	<input type="checkbox"/> ¹	<input type="checkbox"/> ²
4	The aid would help women to understand their prognosis after treatment	<input type="checkbox"/> ¹	<input type="checkbox"/> ²
5	The aid would help women to understand why treatment is recommended for DCIS	<input type="checkbox"/> ¹	<input type="checkbox"/> ²
6	The aid would help women to understand their treatment options	<input type="checkbox"/> ¹	<input type="checkbox"/> ²
7	I like that DCIS is described in this aid as <u>not</u> breast cancer as we commonly think of breast cancer	<input type="checkbox"/> ¹	<input type="checkbox"/> ²
8	I like that DCIS is described in this aid as a risk of developing into breast cancer	<input type="checkbox"/> ¹	<input type="checkbox"/> ²
9	Overall, I like the content of the aid	<input type="checkbox"/> ¹	<input type="checkbox"/> ²
10	Overall, I <u>dislike</u> the format of the aid	<input type="checkbox"/> ¹	<input type="checkbox"/> ²
11	This aid would help me to communicate with women newly diagnosed with DCIS	<input type="checkbox"/> ¹	<input type="checkbox"/> ²
12	Women with DCIS will like this aid	<input type="checkbox"/> ¹	<input type="checkbox"/> ²
13	I would use this aid regularly	<input type="checkbox"/> ¹	<input type="checkbox"/> ²

Diagrams

		Disagree	Agree
1	I like the diagrams of DCIS and invasive breast cancer in the breast on Page 1 of the aid	<input type="checkbox"/> ¹	<input type="checkbox"/> ²
2	I like the diagrams of breast conserving surgery and mastectomy on Page 3 of the aid	<input type="checkbox"/> ¹	<input type="checkbox"/> ²
3	I like the diagrams of weighing scales on Page 4, 5 & 6 of the aid	<input type="checkbox"/> ¹	<input type="checkbox"/> ²
4	I like the risk diagrams on Page 7, 8 & 9 of the aid	<input type="checkbox"/> ¹	<input type="checkbox"/> ²

Are there any comments you would like to make about the diagrams in the aid?

Barriers

		Disagree	Agree
1	This aid is <i>not</i> appropriate for women with only primary school education	<input type="checkbox"/> ¹	<input type="checkbox"/> ²
2	This aid is <i>not</i> appropriate for women from all cultural backgrounds	<input type="checkbox"/> ¹	<input type="checkbox"/> ²
3	Using this aid would make my consultations too long	<input type="checkbox"/> ¹	<input type="checkbox"/> ²
4	This aid would make women too anxious	<input type="checkbox"/> ¹	<input type="checkbox"/> ²
5	Using this aid would change my consultation style	<input type="checkbox"/> ¹	<input type="checkbox"/> ²

Are there any comments you would like to make about the above barriers or any other barriers to using this aid?

Are there any other changes you would like to make to the aid? Please indicate page number and paragraph:

THANK YOU FOR EVALUATING THE DCIS COMMUNICATION AID