

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

---

Simone Elizabeth De Morgan

BMedSci (Hons)

Doctor of Philosophy (Behavioural Science)

School of Medicine and Public Health

University of Newcastle

May 2012

*This thesis contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. I give consent to this copy of my thesis, when deposited in the University Library\*\*, being made available for loan and photocopying subject to the provisions of the Copyright Act 1968. (\*\*Unless an Embargo has been approved for a determined period.)*

Simone De Morgan  
University of Newcastle  
May 2012

# Acknowledgements

---

*I am grateful to have Professor Sally Redman as my primary supervisor and mentor. Her exceptional intellect, creativity, commitment and humour were invaluable to me.*

*Professor Phyllis Butow generously agreed to be my supervisor when Professor Jill Cockburn died. I am grateful to Professor Butow for her immense knowledge and encouragement.*

*I also appreciate the encouragement I received from Emeritus Professor Tom Reeve, Dr Anne Kricker and Professor Alex Barratt.*

*A special thank you to Professor Catherine d'Este who provided advice regarding the statistical analyses in this thesis.*

*I was fortunate to receive support to undertake my study from the National Health and Medical Research Council through a Public Health Post Graduate Scholarship.*

*Thank you to my family and friends who supported and encouraged me in my research especially Nicole Rankin, Megan Blaxland, Phillip Mar, Tamara Shatar, Christopher McLean and Stephanie Brown.*

*Lastly, and most importantly, thank you to my husband Stephen Eccleshall who made this thesis possible.*

*This thesis is dedicated to*  
*two women who died of breast cancer*  
*during the period of my study*

*my mother*  
*Margaret Josephine Brown*

*and*

*my supervisor*  
*Professor Jill Cockburn*

# Table of Contents

---

<b>Abstract</b>		<b>Page 1</b>
<b>Introduction</b>		<b>Page 3</b>
<b>1</b>	<b>Introduction</b>	<b>Page 4</b>
1.1	What is ductal carcinoma in situ (DCIS)?	Page 5
1.2	Outline of the chapters in this thesis	Page 7
<b>Chapter 1</b>	<b>The experiences of women diagnosed with ductal carcinoma in situ (DCIS): a synthesis of qualitative and quantitative evidence in a systematic review</b>	<b>Page 15</b>
<b>1</b>	<b>Introduction</b>	<b>Page 16</b>
<b>2</b>	<b>Methods</b>	<b>Page 18</b>
2.1	Selection criteria	Page 18
2.2	Search strategy	Page 18
2.3	Study quality assessment	Page 19
2.4	Data synthesis	Page 26
2.5	Reflexivity	Page 28
<b>3</b>	<b>Results</b>	<b>Page 29</b>
3.1	Study selection	Page 29
3.2	Study characteristics	Page 31
3.3	Study quality and methodological limitations	Page 34

3.4	The experiences of women diagnosed with DCIS	Page 54
<b>4</b>	<b>Discussion</b>	<b>Page 88</b>
4.1	Methodological considerations	Page 88
4.2	Significance of review findings	Page 89
4.3	Future research about the experiences of women with DCIS	Page 94
4.4	Limitations of the review	Page 97
4.5	Conclusions	Page 97
<b>Chapter 2</b>	<b>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</b>	<b>Page 109</b>
<b>1</b>	<b>Introduction</b>	<b>Page 109</b>
1.1	Aims of the study	Page 112
<b>2</b>	<b>Methods</b>	<b>Page 115</b>
2.1	Study population	Page 115
2.2	Sampling and participation	Page 115
2.3	Comparison of participants and eligible non-participants	Page 120
2.4	Measures	Page 121
2.5	Data analysis	Page 125
<b>3</b>	<b>Results</b>	<b>Page 127</b>

3.1	Sample characteristics	Page 127
3.2	Aim 1: the experiences of women with DCIS	Page 128
3.3	Aim 2: What factors are associated with poor knowledge about DCIS?	Page 143
3.4	Aim 3: What factors are associated with confusion about DCIS?	Page 155
<b>4</b>	<b>Discussion</b>	<b>Page 173</b>
4.1	Limitations of the study	Page 176
4.2	Conclusions	Page 177
<b>Chapter 3</b>	<b>Key communication elements for effectively communicating with women diagnosed with ductal carcinoma in situ (DCIS)</b>	<b>Page 183</b>
<b>1</b>	<b>Descriptive review of the communication literature</b>	<b>Page 186</b>
1.1	Review of the uncertainty communication literature	Page 186
1.2	Review of other relevant areas of the communication literature	Page 196
<b>2</b>	<b>Development of the Key Communication Elements (DCIS)</b>	<b>Page 200</b>
2.1	Process of developing the Key Communication Elements (DCIS)	Page 200
2.2	Type of evidence used to inform recommendations	Page 202
2.3	Categorising the evidence	Page 203
2.4	Development of each recommendation from the evidence	Page 204

<b>3</b>	<b>Reviewers' feedback about the Key Communication Elements (DCIS)</b>	<b>Page 220</b>
<b>4</b>	<b>Discussion</b>	<b>Page 245</b>
4.1	Practice implications	Page 246
4.2	Conclusions	Page 247
<b>Chapter 4:</b>	<b><i>"Well, have I got cancer or haven't I?"</i> How well do doctors communicate a diagnosis of ductal carcinoma in situ (DCIS) with women: opportunities for improving practice</b>	<b>Page 267</b>
<b>1</b>	<b>Introduction</b>	<b>Page 268</b>
<b>2</b>	<b>Methods</b>	<b>Page 270</b>
2.1	Setting	Page 270
2.2	Development of study design and procedures	Page 270
2.3	Ethics approval for the study	Page 272
2.4	Funding	Page 272
2.5	Study population	Page 274
2.6	Recruitment and participation of women diagnosed with DCIS	Page 274
2.7	Recruitment and participation of surgeons	Page 276
2.8	Sample size	Page 277
2.9	Data analysis	Page 277
<b>3</b>	<b>Results</b>	<b>Page 281</b>



3.1	Sample	Page 281
3.2	Communication about key aspects of the diagnosis of DCIS during consultations	Page 283
3.3	Are there differences between surgeons in their communication about DCIS?	Page 318
3.4	Do surgeons communicate about DCIS in the same way to different women?	Page 324
<b>4</b>	<b>Discussion</b>	<b>Page 337</b>
4.1	Limitations of the study	Page 343
4.2	Practice implications	Page 346
4.3	Conclusions	Page 348
<b>Chapter 5</b>	<b>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</b>	<b>Page 355</b>
<b>1</b>	<b>Introduction</b>	<b>Page 356</b>
<b>2</b>	<b>Methods</b>	<b>Page 357</b>
2.1	Development of the CA	Page 357
2.2	Methodology for pilot testing the CA	Page 363
<b>3</b>	<b>Results</b>	<b>Page 365</b>
3.1	Pilot testing the CA with women diagnosed with DCIS	Page 365
3.2	Pilot testing the CA with clinicians	Page 373
3.3	Revision of the CA	Page 382

<b>4</b>	<b>Discussion</b>	<b>Page 384</b>
4.1	Limitations of the study	Page 385
4.2	Practice implications	Page 386
4.3	Conclusions	Page 386
	<b>Discussion</b>	<b>Page 391</b>
<b>1</b>	<b>Discussion</b>	<b>Page 391</b>
1.1	The challenge of communicating about a non-invasive cancer	Page 392
1.2	The challenge of communicating about uncertainty	Page 398
1.3	Future research	Page 402
<b>2</b>	<b>Conclusions</b>	<b>Page 404</b>

# List of Tables

---

## Chapter 1

Table 1.1	Search strategy for the review	Page 19
Table 1.2	Criteria for appraising the quality of observational studies	Page 22
Table 1.3	Criteria for appraising the quality of qualitative studies	Page 24
Table 1.4	Measures used in the observational studies in the review	Page 32
Table 1.5	Characteristics of the studies included in review	Page 39
Table 1.6	Themes and subthemes developed from the data	Page 54
Table 1.7	Key findings from the review	Page 78

## Chapter 2

Table 2.1	The aims of the study	Page 113
Table 2.2	Comparison of participants and eligible non-participants according to age, area of residence, or country of birth	Page 120
Table 2.3	Characteristics of study sample (N=144)	Page 127
Table 2.4	Women's description of their diagnosis	Page 129
Table 2.5	Women's knowledge about DCIS	Page 130
Table 2.6	Satisfaction with information about the diagnosis and treatment of DCIS	Page 132
Table 2.7	Decisional conflict amongst women by the Decisional Conflict Scale (DCS)	Page 134
Table 2.8	Perceived level of involvement in treatment decision-making amongst women	Page 135
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 (DCS)	Page 136
Table 2.10	Satisfaction with the perceived level of involvement in treatment decision-making amongst women	Page 137
Table 2.11	Confusion amongst women about aspects of their diagnosis and treatment	Page 138

Table 2.12	Worry amongst women relating to their diagnosis	Page 140
Table 2.13	Anxiety and depression amongst women by the HADS	Page 141
Table 2.14	Number of women who consulted with a psycho-social health professional	Page 142
Table 2.15	Factors significantly associated with poor knowledge, that is, not knowing that DCIS cannot metastasize (univariate analyses)	Page 145
Table 2.16	Relationship between poor knowledge about whether DCIS can metastasize and participant socio-demographic characteristics (unadjusted)	Page 146
Table 2.17	Relationship between poor knowledge about whether DCIS can metastasize and information (unadjusted)	Page 147
Table 2.18	Relationship between poor knowledge about whether DCIS can metastasize and consultation with a psycho-social health professional (unadjusted)	Page 148
Table 2.19	Relationship between poor knowledge about whether DCIS can metastasize and worry relating to the DCIS diagnosis (unadjusted)	Page 149
Table 2.20	Relationship between poor knowledge about whether DCIS can metastasize and anxiety by HADS ( $\geq 11$ vs $< 11$ ; $\geq 8$ vs $< 8$ ) (unadjusted)	Page 150
Table 2.21	Relationship between poor knowledge and confusion about whether DCIS can metastasize (unadjusted)	Page 151
Table 2.22	Relationship between poor knowledge about whether DCIS can metastasize and high decisional conflict (unadjusted)	Page 152
Table 2.23	Knowledge about DCIS according to type of surgery	Page 153
Table 2.24	Relationship between poor knowledge about whether DCIS can metastasize and radiotherapy (unadjusted)	Page 153
Table 2.25	Factors significantly associated with poor knowledge, that is, not knowing that DCIS cannot metastasize (logistic regression analyses)	Page 155
Table 2.26	Factors significantly associated with confusion about whether DCIS can metastasize (univariate analyses)	Page 158

Table 2.27	Relationship between confusion about whether DCIS can metastasize and participant socio-demographic characteristics (unadjusted)	Page 160
Table 2.28	Relationship between confusion about whether DCIS can metastasize and information (unadjusted)	Page 162
Table 2.29	Relationship between confusion about whether DCIS can metastasize and consultation with a psycho-social health professional (unadjusted)	Page 163
Table 2.30	Relationship between confusion about whether DCIS can metastasize and worry relating to the DCIS diagnosis (unadjusted)	Page 164
Table 2.31	Relationship between confusion about whether DCIS can metastasize and anxiety by HADS ( $\geq 11$ vs $< 11$ ; $\geq 8$ vs $< 8$ ) (unadjusted)	Page 165
Table 2.32	Relationship between confusion about whether DCIS can metastasize and high decisional conflict (unadjusted)	Page 166
Table 2.33	Confusion about whether DCIS can metastasize amongst women according to type of surgery	Page 167
Table 2.34	Odds ratio estimates for the relationship between confusion about whether DCIS can metastasize and type of surgery (versus no surgery)	Page 167
Table 2.35	Relationship between confusion about whether DCIS can metastasize and radiotherapy (unadjusted)	Page 168
Table 2.36	Factors significantly associated with confusion about whether DCIS can metastasize (logistic regression analyses)	Page 170
Table 2.37	Key findings from the cross-sectional survey of women with DCIS (N=144)	Page 171
<b>Chapter 3</b>		
Table 3.1	Key communication elements for effectively communicating with women diagnosed with ductal carcinoma in situ (DCIS)	Page 223
<b>Chapter 4</b>		
Table 4.1	Selected Key Communication Elements (DCIS) included in this study	Page 278

Table 4.2	Characteristics of women with DCIS (n=30)	Page 282
Table 4.3	Number (percentage) of consultations (n=30) in which surgeons communicated in accord with each of the selected Key Communication Elements (DCIS)	Page 284
Table 4.4	Number (percentage) of consultations (n=30) in which surgeons communicated in accord with Key Communication Element (DCIS) 1	Page 287
Table 4.5	Terms and euphemisms used to describe the woman's diagnosis as <u>not</u> invasive breast cancer	Page 288
Table 4.6	Number (percentage) of consultations (n=30) in which surgeons communicated in accord with Key Communication Element (DCIS) 2	Page 291
Table 4.7	Number (percentage) of consultations (n=30) in which the following key terms were used to describe the woman's diagnosis	Page 292
Table 4.8	Number (percentage) of consultations (n=30) in which surgeons communicated in accord with Key Communication Elements (DCIS) 3i-3ii	Page 294
Table 4.9	Number (percentage) of consultations (n=30) in which surgeons communicated in accord with Key Communication Element (DCIS) 3iii	Page 295
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	Page 296
Table 4.11	Number (percentage) of consultations (n=30) in which surgeons communicated in accord with Key Communication Elements (DCIS) 4i-4v	Page 302
Table 4.12	Number (percentage) of consultations (n=30) in which surgeons communicated in accord with Key Communication Element (DCIS) 5i	Page 307
Table 4.13	Number (percentage) of consultations (n=30) in which surgeons communicated in accord with Key Communication Elements (DCIS) 5ii-5iii	Page 309
Table 4.14	Number (percentage) of consultations (n=30) in which surgeons communicated in accord with the Key Communication Element (DCIS) 6	Page 312

Table 4.15	Number (percentage) of consultations (n=30) in which surgeons communicated in accord with the Key Communication Element (DCIS) 7	Page 315
Table 4.16	Number (percentage) of consultations (n=30) in which surgeons communicated in accord with the Key Communication Elements (DCIS) 8-10	Page 317
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	Page 319
Table 4.18	Number (percentage) of surgeons (n=13) who used the following terms to describe the woman's diagnosis	Page 323

## **Chapter 5**

Table 5.1	Framework to guide development and evaluation of the CA in a pilot study	Page 358
Table 5.2	<i>Key Communication Elements (DCIS)</i> that informed the content of the CA	Page 360
Table 5.3	Demographic and treatment-related characteristics of women with DCIS who participated in the pilot study (n=18)	Page 366
Table 5.4	Women's (n=18) perceptions of the benefits and emotional impact of the CA	Page 369
Table 5.5	Women's perceptions of the diagrams in the CA	Page 372
Table 5.6	Gender and practice related characteristics of clinicians (n=7)	Page 374
Table 5.7	Clinicians' (n=7) perceptions of the benefits and emotional impact of the CA	Page 376
Table 5.8	Clinicians' perceptions of the diagrams in the CA	Page 380

# List of Figures

---

## **Chapter 1**

Figure 1	Study selection	Page 30
----------	-----------------	---------

## **Chapter 2**

Figure 1	Sampling procedure for the study	Page 116
----------	----------------------------------	----------

Figure 2	Participation in the study	Page 118
----------	----------------------------	----------

## **Chapter 4**

Figure 1	Diagnostic and treatment pathway for women involved in the study	Page 273
----------	--	----------



# List of 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.
- Appendix 2.2 NSWCCR letter to doctors
- Appendix 2.3 NSWCCR letter to women
- Appendix 2.4 Study investigators letter to women
- Appendix 2.5 Information sheet about the study
- Appendix 2.6 *About your diagnosis* survey
- Appendix 2.7 Test-retest reliability calculations for all survey items

## Chapter 4

- Appendix 4.1 Protocol for BreastScreen counsellors or nurses
- Appendix 4.2 Protocol for research nurse
- Appendix 4.3 Refusal form completed by research nurse
- Appendix 4.4 Coding log form for women
- Appendix 4.5 Coding log form for surgeons
- Appendix 4.6 Information for surgeons
- Appendix 4.7 Consent form for surgeons
- Appendix 4.8 Survey for surgeons

- Appendix 4.9 Protocol for surgeons
- Appendix 4.10 Comment sheet for surgeons
- Appendix 4.11 Information sheet for women
- Appendix 4.12 Survey for women
- Appendix 4.13 Consent form for women
- Appendix 4.14 Coding manual for study

## **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.
- 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](http://www.canceraustralia.gov.au)
- Appendix 5.3 *How to Use* guide for CA
- Appendix 5.4 Study letter of invitation for women with DCIS
- Appendix 5.5 Study information sheets for women and clinicians
- Appendix 5.6 Consent form for women with DCIS
- Appendix 5.7 Structured interview schedule for women with DCIS
- Appendix 5.8 Study letter of invitation for clinicians
- Appendix 5.9 Consent form for clinicians
- Appendix 5.10 Survey for clinicians

# 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.