



SUPPORTING RURAL WOMEN WITH BREAST CANCER PROJECT

Evaluation of the Role of the Breast Care Nurse at Toowoomba Base Hospital

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Executive Summary

The Supporting Rural Women with Breast Cancer Project started in Toowoomba in January 2005 with a Breast Care Nurse in a full time position in July 2005. The aim of the project is to develop and implement a revised multidisciplinary model of care resulting in the reorganisation and enhanced coordination of breast care services provided by Toowoomba Health Service District.

A key deliverable under the service agreement with the Australian Government is the implementation of an evaluation plan and the compilation of an evaluation report. A decision on continuation of project initiatives will be informed in part by the results of the evaluation reported herein which was conducted by the Centre for Rural and Remote Area Health (CRRAH) based at the University of Southern Queensland.

Structured questionnaires were used for both patient and stakeholder feedback. Fifty-one former breast cancer patients were interviewed by telephone. Twenty questions polled patients' views on their access to the Breast Care Nurse and the nurse's role in coordinating care, referral to other health professionals, and in providing information and psychosocial, emotional and practical support.

Stakeholders received the questionnaire through the Toowoomba Health Services internal email system and returned completed questionnaires by reply paid mail to CRRAH. The questions were designed to provide views on the support that the Breast Care Nurse had made to a multi disciplinary treatment regimen. Views on the reasons for success or failure of the programme were also elicited.

Widespread knowledge of the Breast Care Nurse prior to breast cancer treatment was poor; patients were unaware of the Breast Care Nurse until their first contact with her which was usually at the Surgical Outpatients Clinic held at the BreastScreen Toowoomba Service. More information about the position and role could be made available through GPs.

Results from the patients revealed enormous gratitude for the support that they received from the Breast Care Nurse. There was overwhelming agreement that the timing of contact, ease of accessibility, information provided and support offered was extremely valuable in making their treatment and recovery easier. The vast majority of participants would recommend to their friends that they should attend hospitals with a Breast Care Nurse.

Similar sentiments about the value of the Breast Care Nurse were received from stakeholders who recognised the benefit of the position not only to patients but also to the multidisciplinary team members in terms of coordination and liaison. However stakeholders did believe that a multidisciplinary team approach had not yet been fully achieved.

The importance of maintaining a full time position of Breast Care Nurse was noted by both patients and stakeholders as accessibility of the nurse to patients was a key feature of the success of the programme.

The study was in agreement with several other Australian reports all of which have demonstrated the success of dedicated Breast Care Nurses. The recommendation from the evaluation team is that the position of a full time Breast Care Nurse should be maintained. The Breast Care Nurse model is one that could be used successfully to support other medical conditions.

Introduction

Breast cancer continues to be the most commonly diagnosed cancer and cause of death of women in Australia¹. Greater access to screening services and improved diagnosis have contributed to increased incidence from 5,318 cases in 1983 to 11,788 in 2003. However, with earlier detection and improved treatment deaths decreased from 31.0 deaths per 100,000 females in 1990 to 23.4 deaths per 100,000 females in 2004². The decline has been even greater in the target age group of 50-69 years, with the death rate falling from 69 per 100,000 women in 1990 to 51 per 100,000 in 2004³. One-year and five-year relative survival has increased from 93.2% to 96.7% and 70.9% to 86.6%, respectively from 1982-86 to 1998-2002².

Clinical practice guidelines for the management of early breast cancer were established in 1995 by Australia's National Health and Medical Research Council National Breast Cancer Centre. The second edition of these guidelines which appeared in 2001⁴ strongly advocated the offering of psychosocial support to women with breast cancer as outlined in a previous report⁵.

A study of women with breast cancer concluded that the psychosocial guidelines adequately reflected consumer opinions and identified priority areas for clinicians to address in providing psychosocial support to women with breast cancer⁶. The extent of the provision of information, support and psychosocial care as outlined in the clinical practice guidelines has also been determined⁷. Over 80% of women received care in accord with half of the 12 target guidelines, but the need for more programmes to improve access to information was noted.

In addition to the clinical practice guidelines, a number of strategies have been employed to improve the psychological wellbeing of women with breast cancer. For example the Breast Cancer Support Service provided by the Cancer Council in states and territories, supports women with breast cancer on a one-to-one basis with women who themselves have had breast cancer. Survey results show that women who meet someone else with similar experiences consider this to be beneficial and 89% said they would definitely recommend it to others⁸.

Another strategy is that of the specialist nurses (referred to most frequently as Specialist Breast Nurses or Breast Care Nurses) who provide continuity of support to breast cancer patients from diagnosis to completion of treatment. A number of trials in the UK showed that breast care nurses enhance the early recognition of support needs, decrease psychological distress, and improve continuity of care and understanding of the disease and its treatment⁹⁻¹³.

Specially trained Breast Care Nurses have been in existence in Australia for over thirty years and the role of this specialist nurse was described in detail in 1999¹⁴.

The national Breast Cancer Support Service (BCSS) began operation in Victoria in 1975 and provided Breast Care Nurses with one-day training at the Anti-Cancer Council of Victoria^{a15}. However the number of Breast Care Nurses was small with their distribution largely in the metropolitan areas. A national survey of women with early breast cancer undertaken in 1997 revealed that only 55% of women saw a Breast Care Nurse on one occasion, 26% saw a breast care nurse three or more times and only 14% had received structured support from a breast care nurse^{16, 17}. Comparison between women who did not see a breast nurse and those women who

^a Now known as the Cancer Council of Victoria

had three or more contacts revealed that the latter group received more information about side effects, clinical trials, self support and family support¹⁶.

The Specialist Breast Nurse Demonstration Project demonstrated that specialist nurses could be effectively administered across Australia¹⁸ and a multi-centre study compared patients supported by the specialist breast care nurses with demographically similar controls¹⁹. Data from patients were collected with the National Consumer Survey developed for the 1997 national survey¹⁶. Patient data demonstrated a favourable response to the support of the breast care nurse. Health professionals reported that the nurses improved functionality of the multi disciplinary health teams and provided valuable information to patients at all stages of their treatment.

Further evidence of the value of the breast care nurses comes from Leibert and colleagues who described the National Breast Cancer Centre clinical pathway for specialist breast nurses in Australia²⁰. Evaluation of the model by a member of the team is reported²¹ as were the perceptions of women of the care received from a specialist breast care nurse²². The latter study demonstrated that the breast care nurse was perceived as a valuable link between women and the multi-disciplinary team, with continuity of care being rated as a major benefit. Over 80% of women reported the breast care nurse to be effective in providing information and emotional support.

Other studies conducted in Victoria^{23,24} and New South Wales²⁵ evaluating consumers, the breast care nurses themselves and other health professionals all demonstrate the overall value of the speciality.

Evaluations of federally funded breast care nurse programmes within the states have also been undertaken. These are largely unpublished however papers have been presented at various workshops and conferences. In those evaluations the emotional and practical support provided by the breast care nurses is consistently reported to be of considerable value and patients say they would recommend the service to friends or relatives if they required breast cancer treatment.

All results would suggest that the specialised role is well accepted by other health professionals and is perceived by patients to have provided an invaluable contribution to their support.

However despite the positive overwhelming positive response widespread introduction of Breast Care Nurses has been very slow and there is still no uniformity across or even within states in names or qualifications. Access to Breast Care Nurses remains difficult for many women especially in rural and remote areas²⁴. Concern has also been expressed that even in metropolitan areas where most of the nurses work, access may not be at a time that is most useful²⁶.

The term Breast Care Nurse is still a generic one for any nurse who has received specific training in breast cancer care. A study undertaken in 2000 for the Victorian Department of Human Services concluded that the current breast care nursing workforce lacked a common approach to women and that role development had occurred in an ad hoc and variable manner²⁷. A 2002 Victorian study highlighted the wide variation in implementation of the role, level of educational preparation, approach to care delivery, and skill level²⁸. The study contributed to the formation of the Specialist Breast Nurse Competencies Project Team in 2002 to develop competencies for breast care nurses.

Breast care nurses have been slowly being introduced in to Queensland. In the public sector prior to 2001 there were only four positions and six more were established that year. Additional positions have been established since that time. Of the current 16 positions within Queensland Health, three in Barcaldine, Mitchell and Emerald are funded by the Breast Cancer Association of Queensland²⁹.

In Queensland the term Specialist Breast Care Nurse is used in the public sector to denote nurses whose role is consistent with that outlined in the National Breast Cancer Centre competency standards³⁰.

The Supporting Rural Women with Breast Cancer Project, a Commonwealth initiative started in Toowoomba in January 2005. The aim of the project is to develop and implement a revised multidisciplinary model of care resulting in the reorganisation and enhanced coordination of breast care services provided by Toowoomba Health Service District. A central role in the project is that of a Specialist Breast Care Nurse in providing supportive care and facilitating the movement towards a multidisciplinary model of care. From January to July 2005 a part-time Breast Care Nurse was in position. In June 2005 a new full-time Breast Care Nurse was appointed and has remained so to the date of this report.

A key deliverable under the service agreement with the Australian Government is the implementation of an evaluation plan and the compilation of an evaluation report. Toowoomba Health Service District is expected to make decisions on continuation of the project initiatives based on the combined results of an evaluation and a separate analysis of clinical indicators associated with project implementation.

A two-stage evaluation process, encompassing both patient and key stakeholder feedback, was conducted by the Centre for Rural and Remote Area Health (CRRAH). The results of that evaluation are contained in this report.

Methodology

Patient Feedback

A questionnaire (Appendix 1) was developed after consultation with stakeholders and review of other client/consumer satisfaction questionnaires that had been used for similar studies on breast cancer support programmes in other locations. These questionnaires are unpublished but were made available to the research team.

The questionnaire was administered through telephone interview and explored patients' awareness of and access to the Breast Care Nurse, coordination of care offered and the value and timing of information and support given by the Breast Care Nurse.

The questionnaire consisted of 20 questions each of which required a yes/no response or selection of an answer from a Likert scale. At the end of the interview participants were asked if they would like to offer additional comments.

The study was approved by the Human Research Ethics Committees at both the University of Southern Queensland's (USQ) and the Toowoomba Health Service District.

All participants consented to be interviewed. Verbal consent first was obtained by the Breast Care Nurse who then advised the research team of the patient's name and contact details. A plain language statement and consent form (Appendix 2) was sent to each participant. Receipt of a signed consent form was required for any data to be used.

The 20 – 30 minute interviews were conducted by telephone between 28th February 2007 and 19th April 2007 by an experienced female project officer.

Stakeholder Feedback

The original proposal called for determining stakeholder feedback through a combination of focus groups and a questionnaire. However upon advice from stakeholders the focus groups were deemed not to be necessary.

Consequently stakeholder's views on the position of the Breast Care Nurse were obtained through a second questionnaire (Appendix 3). The questionnaires were distributed to relevant staff by internal Toowoomba Health Service District e-mail on 16th April 2007 with a deadline for return on 27th April 2007.

Stakeholders were given the opportunity to send the questionnaire back electronically to CRRAH, return it in hard copy in a reply paid envelope or to contact CRRAH and complete the questionnaire by telephone interview.

Results from Patient Questionnaire

Participants

Since the establishment of the Breast Care Nurse in July 2005 approximately 120 women were offered support following their diagnosis. An unrecorded number of women diagnosed and treated prior to July 2005 also were contacted by the Breast Care Nurse to ask if they wanted assistance.

Sixty-nine women were contacted by the Breast Care Nurse. Six declined to participate and 63 gave verbal agreement that they were prepared to be interviewed. Subsequent difficulties by the evaluation team in establishing contact or unavailability during April 2007 resulted in a total of 51 interviews being conducted.

Dates of birth of the women who were interviewed ranged from 1928-1968 (Table 1).

Table 1. Ages of women interviewed

Age band	Number	Percentage
<40	1	1
40 – 49	10	20
50 – 59	19	37
60 - 69	12	24
70 - 79	9	18
Total	51	

Home location of participants

The interviewed women came from both regional and rural areas. Fourteen came from Toowoomba and a further five from locations within 20 kilometres of Toowoomba. The home locations of the other 32 were bounded by Gatton (east), Nanango (north), Texas (south) and Cunnamulla (west).

The distance to a medical facility for the 32 women outside of Toowoomba and environs ranged from 4 to 100 kilometres. Distances to Breast Cancer Specialist facilities in Toowoomba for the entire cohort ranged from 0 to 800 kilometres.

Q1. First contact with the Breast Care Nurse

A quarter of the women on the study had their first contact with the part-time Breast Care Nurse who was in position prior to July 2005 (Table 2). These 12 women also had contact with the incumbent after July 2005. Three quarters only had contact with the incumbent.

Table 2. First contact with the breast care nurse

First contact	Number	Percent
Before July 2005	12	24
July 2005 onwards	39	76
Total	51	

Seven of the 12 pre July 2005 women had completed treatment prior to July 2005 but were contacted and supported by the present Breast Care Nurse in their post treatment period (Table 3).

Table 3. Date of completion of treatment

Date completion	Number	Percent
Before July 2005	7	14
July – December 2005	8	16
2006	29	57
2007	7	14
Total	51	

Q2. Surgery and treatment regimen

All women had surgery which involved lumpectomy(ies), mastectomy or both; similar numbers had chemotherapy or radiotherapy with a little over a quarter having both chemotherapy and radiotherapy (Table 4). Radiotherapy treatment occurs in Brisbane which is another 120 kilometres east of Toowoomba. Just under half of the women began hormonal medication after their chemotherapy or radiotherapy treatment was completed.

Table 4. Surgery and treatment regimen

Regimen	Number	Percent
Surgery	51	100
Chemotherapy (C)	23	45
Radiotherapy (R)	26	51
C + R	14	27
Hormonal	24	47

A. Awareness of the Breast Care Nurse

Q3. How did you find out about the Breast Care Nurse?

Women heard about the Breast Care Nurse mostly from the Breast Care Nurse herself or from the staff at the BreastScreen clinic (Table 5).

Table 5. Source of information about the Breast Care Nurse

Source	Number	Percent
BCN introduced herself	42	82
Staff at BreastScreen	13	25
Hospital doctor or nurse	5	10
Other	2	4
Private surgeon	1	2
GP	1	2
A breast cancer support volunteer	1	2
Friend or family member	1	2
Total	66*	

* Number exceeds 51 as some participants offered two sources of information

Q4. Who explained the role of the Breast Care Nurse?

For the majority of women it was the Breast Care Nurse who explained her own role (Table 6).

Table 6. Source of explanation of the role of the Breast Care Nurse

Source	Number	Percent
Breast Care Nurse	43	84
Staff at BreastScreen	7	14
Hospital doctor or nurse	3	6
Private surgeon	2	4
GP	1	2
Other	0	0
Nobody	0	0
	56*	

* Number exceeds 51 as some participants offered two sources of information

Q5. When was your first contact with the Breast Care Nurse?

The vast majority of participants had first contact with the Breast Care Nurse either at diagnosis or time leading to surgery (Table 7).

Table 7. Patients first contact with the Breast Care Nurse

First contact with BCN	Number	Percent
At diagnosis or within two days	28	55
During time leading to surgery	19	37
After surgery before discharge	2	4
When returned home	0	0
At first follow up	0	0
Other	2	4
Total	51	

Q6. How do you feel about the timing of your first contact with the Breast Care Nurse?

All but four of the 49 women who responded to the question said the timing was right (Table 8). Three women who had their first contact in the time leading to biopsy but before diagnosis described contact as a little early. One woman who had already had surgery before contact was made viewed the contact as a little late.

Table 8. Views on the timing of the first contact with the Breast Care Nurse

Time of first contact	Number	Percent
Far too early		
A little early	3	6
Right time	45	92
A little late	1	2
Far too late		
Total	49	

B. Access to the Breast Care Nurse

The Breast Care Nurse keeps track of patient visits to the hospital for treatment, and arranges to see the patient during these visits. In between visits, women are able to contact the Breast Care Nurse (by phone or in person) in patient-initiated contacts.

Q7. Was enough time generally made available during the consultation?

All respondents considered that the time made available for consultation was about right (Table 9).

Table 9. Views on the amount of time given for consultation with the Breast Care Nurse

Timing for consultation	Number	Percent
Very short		
Short		
Just about right	50	100
Too long		
Much too long		
Total	50	

Q8. Were you able to contact the Breast Care Nurse when ever you wanted to?

The vast majority of responses indicated that contact with the Breast Care Nurse was easy or very easy (Table 10).

Table 10. Views on the ease of contact with the Breast Care Nurse

Ability to contact	Number	Percent
Very difficult		
Difficult	1	2
Just about right	6	12
Easy	18	36
Very easy	25	51
Total	50	

Q9. How would you have preferred your appointments with the Breast Care Nurse?

In response to the question on preference of appointments a quarter of the women said that the Breast Care Nurse should make the choice (Table 11). However 65% would have preferred to have had their appointments when they wanted them. Only four of the interviewees indicated they would have preferred appointments on a regular basis throughout.

Table 11. Preferences on the manner of making appointments with the Breast Care Nurse

Preference of appointments	Number	Percent
Regular	4	8
When I wanted them	33	65
As set up by the Breast Care Nurse	13	25
Total	50	

Q10. How satisfied were you that the consultations fitted with your treatment?

No-one considered consultations to be badly timed (Table 12). There were only three women who believed that consultations could have been better timed. All of these women were in hospital for surgery when they met the Breast Care Nurse.

Table 12. Timing of consultations in relation to stage of treatment

Timing of consultations	Number	Percent
Well timed	48	95
Some could have been better timed	3	6
Badly timed		
Total	51	

Q11. How satisfied were you with your level of contact with the Breast Care Nurse?

Only two of the fifty-one women who were interviewed said that the level of contact was not just about right (Table 13).

Table 13. Views on the level of contact with the Breast Care Nurse

Level of contact	Number	Percent
Far too little	1	2
Too little	1	2
Just about right	48	96
Too much		
Far too much		
Total	50	

Q12. Do you think having the same Breast Care Nurse as your contact person during the treatment was of any benefit?

Only one person considered that having the same Breast Care Nurse as the contact person throughout treatment would not be of benefit (Table 14). The “unsure”, “no benefit” and one of the three “little benefit” responses were all from women who had completed their treatment prior to July 2005.

Table 14. Views on having the same Breast Care Nurse during treatment

Benefit of same BCN	Number	Percent
Unsure	1	2
No benefit	1	2
Yes, a little benefit	3	6
Yes, of great benefit	45	90
Total	50	

C. Coordinating Care

Q13. How would you rate the amount of help from the BCN on the following?

Between 10 and 22 percent of the respondents indicated that individual questions were not applicable to them (Table 15). Of the remainder all the responses were that the amount of help provided was the right amount.

Table 15. Rating of the help offered by the Breast Care Nurse

Help offered	Wanted more	Right amount	Wanted less	N/A
Understanding the roles of the different people involved in your treatment	0	45	0	6
Understanding the information you received from different doctors and health workers	0	46	0	5
Communicating your needs to other health workers	0	40	0	11
Making appointments for you	0	44	0	7
Making the transition to the next stage of your treatment easy	0	45	0	6

D. Information needs

Q14. How would you rate the amount of information you received from the Breast Care Nurse about the following?

For two of the areas a single woman indicated that she would have liked more information (Table 16). The two women who indicated they would have liked less information could not remember if it had come from the Breast Care Nurse or not.

Table 16. Rating of the information provided by the Breast Care Nurse (1)

Information provided	Wanted more	Right amount	Wanted less	N/A
Your cancer	0	45	1	4
Your treatment choices	0	44	1	5
The treatment itself	1	44	1	4
Side effects of the treatment	0	43	2	5
Caring for yourself at home	0	44	1	4
Support services	1	41	1	7

Q15. Do you believe that the Breast Care Nurse?

Ratings of the information provided were extremely positive (Table 17). However for the question on the information about where to find spiritual support, half of the interviewees said this was not applicable. For those for whom it was applicable appropriate, support from the Breast Care Nurse was recognised. Similar responses were received for the question on alternative therapies.

Table 17. Rating of the information provided by the Breast Care Nurse (2)

Information provided	Strongly agree	Agree	Disagree	Strongly disagree	N/A
Allowed you to share your real feelings with her	42	4	0	0	5
Was good at explaining things	41	7	0	0	3
Gave you too much information	0	2	40	6	3
Said things that helped you cope or feel a little better about things	39	4	0	0	7
Offered advice, practical support/information at the times when most needed	41	7	0	0	3
Offered sufficient information of where to seek spiritual support	21	4	2	0	23
Was open to discuss alternative therapies with you	25	5	1	0	20

E. Psychosocial support

Q16. Having contact with the Breast Care Nurse has helped

With very few exceptions there was agreement or strong agreement to all statements related to psychosocial support (Table 18). One woman strongly disagreed to all statements.

Table 18. Rating of the support provided by the Breast Care Nurse

Contact helped you ...	Strongly agree	Agree	Disagree	Strongly disagree	N/A
To deal with your diagnosis	38	5	2	1	5
To make treatment choices	32	4	4	1	10
With communication with your doctor	27	6	1	1	16
To deal with concerns your family had about your cancer	35	4	0	1	11
To express and manage feelings about the cancer	34	7	2	2	4
To deal with side effects	33	6	0	1	11

F. Emotional Support

Q17. How satisfied were you with the emotional support from the Breast Care Nurse?

The majority of respondents were very satisfied with the emotional support that they received from the Breast Care Nurse (Table 19). The woman who indicated she was dissatisfied with the emotional support was also the only person who strongly disagreed with all the statements in Q16 on psychosocial support. She did not answer most other questions in the survey, saying they were not applicable.

Table 19. Rating of the emotional support offered by the Breast Care Nurse

Timing when support was offered	Very Satisfied	Satisfied	Not Satisfied	Very Dissatisfied	N/A
Before treatment	41	6	0	1	2
During treatment	41	4	1	1	3
After treatment finished	40	5	1	1	3

G. Practical Support

Q18. Did the breast nurse provide you with enough help in?

“About right” was the norm for all of the questions (Table 20). A third of the women (17) said that information about getting a prosthesis was not required.

Table 20. Rating of the help offered by the Breast Care Nurse

Type of help that was offered	Not enough	About right	Too much
Offering information re travel and/or accommodation	0	43	0
Getting a prosthesis	0	32	0
Understanding how long I would be in hospital	1	44	0
Understanding what would happen when I was discharged	1	46	0

H. General effect seeing a breast nurse had on you.

Q19. In advising a friend about getting treatment for breast cancer, would you say.....?

Most respondents were quite emphatic that the advice they would offer to their friend would be to choose or prefer a hospital with access to a Breast Care Nurse (Table 19). The consensus was to access a Breast Care Nurse if at all possible but not at the expense of getting treatment at all.

Table 21. Advice offered to friends regarding hospitals with a Breast Care Nurse

Advice offered	Yes	No	Don't know
Only choose a hospital which provides access to a Breast Care Nurse	39	9	2
Prefer a hospital with access to a Breast Care Nurse	46	1	3
Don't worry about whether a Breast Care Nurse is available at the hospital	3	45	2

I. Referral

Q20. Did the Breast Care Nurse suggest or offer you the chance to talk to any of the following groups of people?

The Breast Care Nurse suggested referrals to other health professionals in varying amounts (Table 22).

Table 22. Persons Breast Care Nurse advised patients to talk to

Health professional	Yes	No	Don't know	N/A
A social worker or welfare worker	34	7	5	4
A psychologist	28	8	7	7
A Breast Cancer Support Service volunteer	41	5	2	2
The Queensland Cancer Fund Service	36	9	2	3
A Breast Cancer Support Group	41	6	2	1
A physiotherapist	39	5	2	4
A chemotherapy nurse	17	9	3	22
Your GP	29	9	1	11
Community nurse	23	19	0	8

J. Comments

Forty-seven women offered an additional 76 comments about the service. All the comments are in Appendix 4. These comments were divided into the four categories.

1. Comments about Queensland Health staff and service in general (17 comments) were all very positive

All the girls are wonderful there in the Breast clinic.

Can't speak highly enough about the hospital and chemo unit.

The public system never once let me down - I can't fault it.

2. Comments about the role of the Breast Care Nurse (36 comments) indicated that the role of the Breast Care Nurse was greatly appreciated. All the comments were very positive.

Her services are invaluable - two years on and [she] is still a link if I need it. She already knows you and understands your condition - I rang her about something last week.

Service is invaluable - need female Breast Care Nurse to communicate with - really important having the access to Breast Care Nurse at any time.

I wouldn't have made it without the Breast Care Nurse. I put a lot of my wellness down to Breast Care Nurse's help.

...would have died without her ... completely crashed ... went to pieces. Breast Care Nurse, psychiatrist and social worker provided intensive support for six months. The Breast Care Nurse is still looking after me after chemo.

3. Comments about the specific information offered by the Breast Care Nurse (11) were again positive.

Thank goodness someone explained it - aboriginal people don't understand this stuff - they were very good with me.

You do need a lot of information and she helped me understand it. My husband had already had cancer and chemo so I knew the procedures.

- [she] answered everything -

4. Comments about the personality of the current Breast Care Nurse (12) were enthusiastically offered and were all flattering.

She's definitely irreplaceable - get her to train any other Breast Care Nurse that is hired.

Wonderful! They all need to be as caring as her - a friend as well as a nurse

Now a good friend.

During the course of the interviews other comments were offered to qualify responses to questions. There were four women who noted that their exposure to the Breast Care Nurse had been very limited.

I must have slipped through loop - didn't have as much involvement with her.

One of these was by choice.

I have never considered seeing the Breast Care Nurse - have seen her in the hallways a few times but there has been no contact.

A couple of the pre July 2005 women also did not differentiate between the Breast Care Nurse and BreastScreen nurses in general

[I] saw the Breast Care Nurse and BreastScreen as the same thing.

Results from Stakeholder Questionnaire.

Questionnaires were sent to stakeholders within the areas of the health service listed in Table 23. The questionnaire were sent by internal e-mail and the number of recipients of the questionnaire is not known to the evaluation team. There were 18 responses; 13 from Nursing Officers, three from Medical Officers and two “other” - a representative from a community organisation and a respondent who did not identify their area of work or profession.

Table 23. Area of work

Area
Aboriginal Health
Cancer Care Service
Community Health
Day Hospital
Day Oncology
Director Medical Unit
Director of Nursing
Discharge Planning
General Practice
Infection Control
Medical Imaging
Medical Outpatients
Nurses in Breast Screen
BCN in private hospital
Pathology
Physiotherapy
Preadmission
Pre-anaesthetic Clinic
Private Practice
Surgical Outpatients
Surgical Unit
Theatre Bookings
Other
Total

Q1. How would you describe your awareness of the role of the Breast Care Nurse?

Awareness of the role of the Breast Care Nurse was high among stakeholders (Table 24).

Table 24. Awareness of the role of the Breast Care Nurse

	Nursing Officer	Medical Officer	Other
Very aware	6	2	2
Aware	5	1	
Unclear	1		
Unaware			

Q2. On average, how often have you been in contact with the Breast Care Nurse?

Contact varied from a minimum of weekly to less than monthly (Table 25). Fourteen of the 18 respondents saw the Breast Care Nurse at least weekly.

Table 25. Frequency of contact with the Breast Care Nurse

	Nursing Officer	Medical Officer	Other
Several times a week	8	1	1
Weekly	4		
Fortnightly		1	
Monthly		1	
Less than monthly	1		1

Q3. What do you see as the particular role of the Breast Care Nurse within the treatment team?

Responses were consistent, with stakeholders identifying the Breast Care Nurse as being both the provider of support and information to the patient and also as an important link between a team of health professionals.

- *Support women with breast cancer; invaluable link to information and resources.*
- *Reassurance of patient – streamlining and smooth running of patient through pathway of diagnosis and treatment.*
- *Support for clinical staff and client.*
- *Liaison, coordination, support – holistic and especially emotional.*
- *The Breast Care Nurse provides support and guidance to the client. He/she is an integral link between the client/family and treating medical officers to maintain communication between both parties.*
- *Provides information, education and support for women and men with breast cancer. She also organises x-rays, echoes, service pathology. She follows patients’ treatment throughout and offers support.*
- *Facilitate early diagnosis and patient referrals.*
- *Provides information, education and support for women and men with breast cancer. The Breast Care Nurse follows their treatment and offers and support and organises x-rays, echoes, pathology and wig services while liaising with oncology staff.*
- *Professional link from breast care to other tumour streams of cancer. Toowoomba Base Hospital organiser.*
- *Coordination of services for women undergoing breast surgery – breast clinic appointments, visits from volunteers, demonstration of how to look after drains and wounds.*
- *She has a central role in the management of breast cancer patients. She is the link between the surgeon and other providers and the patient as well as other non medical surgical support. She is the person who often has time to discuss patients’ concerns with them and allay or ease fears.*
- *Education, support and co-ordination of care; the link between the patient and the system.*
- *Provides a coordinated service approach to ensure continuity of care for women with breast cancer. Includes physical and psychosocial aspects of care.*
- *Coordination of care of breast cancer patients and support of these patients and their families.*
- *Support, coordination and counselling.*

Q4. Did the Breast Care Nurse participate in multidisciplinary team meetings, case discussions or reviews?

All but one respondent stated that the Breast Care Nurse participated in multidisciplinary team meetings (Table 26). These responses have to be compared to the responses to Question 14 (page 25). The one respondent who stated “no” was in a senior administrative role.

Table 26. Knowledge of participation of the Breast Care Nurse in team meetings

	Nursing Officer	Medical Officer	Other
Yes	10	3	2
No	1		
Unsure	1		
Cannot comment	1		

Q5. In your view was the Breast Care Nurse able to influence clinical/case management decisions for individual clients?

Most Nursing Officers believed that the Breast Care Nurse was able to influence decisions (Table 27).

Table 27. Influence of the Breast Care Nurse in case management

	Nursing Officer	Medical Officer	Other
Yes	11	1	2
No			
Unsure			
Cannot comment	2	2	

Q6. Would you say the input of the Breast Care Nurse was valued by clinical and nursing staff?

The Breast Care Nurse was clearly valued by all stakeholders (Table 28).

- *Always very helpful and responds promptly. [She] communicates well with staff, patients and their families.*

Table 28. Value of the Breast Care Nurse by clinical and nursing staff

	Nursing Officer	Medical Officer	Other
Yes	12	3	2
No			
Unsure			
Cannot comment	1		

Q7. Do you feel that members of the treatment team have made appropriate referrals to the Breast Care Nurse?

The majority of respondents believed that appropriate referrals had been made. However two respondents did not agree that appropriate referrals had been made (Table 29)

- *Some clinical staff just do not see the need and appear to try to undermine the role.*

- *Some women are disadvantaged because they are unaware of the Breast Care Nurse role that is available at the hospital.*

Table 29. Appropriateness of referrals to the Breast Care Nurse by members of the treatment team

	Nursing Officer	Medical Officer	Other
Yes	9	1	2
No	2		
Unsure	1	2	
Cannot comment	1		

Q8. Did you or any of your patients encounter any difficulties accessing the Breast Care Nurse?

No one ticked the “yes” box. Two respondents commented that difficulties were only encountered by patients in accessing the Breast Care Nurse were when she was on leave (Table 30).

- *Maybe on conference leave and not replaced.*
- *Only if the Breast Care Nurse was engaged with patient care, meetings or unavailable at the time. Messages, phone and email made to Breast Care Nurse always answered and calls, referrals, problem solving outcomes favourable.*

Table 30. Difficulties encountered by patients in accessing the Breast Care Nurse

	Nursing Officer	Medical Officer	Other
Yes			
No	12	1	2
Unsure		1	
Cannot comment	1	1	

Two respondents predicted problems in accessing the Breast Care Nurse in future if the position changed from a full-time to a part-time one.

- *Must continue with Breast Care Nurse making it a full time position within the district.*
- *The Breast Care Nurse currently works full time because of present funding. This will alter in July which may produce a different scenario.*

Q9. Thinking about the Breast Care Nurse role, what if any changes could be made to improve patient outcome?

Five respondents considered that changes could be made. Three considered that more hours were required while two stated that more coordination among different parts of the multidisciplinary team was required (Table 31).

- *Increase hours.*
- *More hours and cover for rostered days off etc.*

- *The work load I believe is too heavy. Long hours must take into account the number of professional meetings beside patients care counselling, face to face contact. Long term this could lead to burn out of the Breast Care Nurse.*
- *Coordination of bookings and appointments i.e. so doubling up is avoided.*
- *Formalise the multidisciplinary team approach to the service.*

Table 31. Changes to the role of the Breast Care Nurse

	Nursing Officer	Medical Officer	Other
Yes, changes required	5		
No changes required	2	2	1
Unsure	2		1
Cannot comment	2	1	

Q10. Do you feel that a Breast Care Nurse is important for ensuring women receive high quality care?

Stakeholders were unanimous in the opinion that the Breast Care Nurse supported high quality care (Table 32).

Table 32. Importance of the Breast Care Nurse in ensuring high quality care

	Nursing Officer	Medical Officer	Other
Yes	12	3	2
No			
Unsure			
Cannot comment	1		

- *Breast Care Nurse saves time and resources.*
- *Important to be able to guide the women through the complex multi-disciplinary areas that are involved in their care.*
- *Breast Care Nurse's role and responsibilities/accountabilities are taken very seriously. The right person in the position will always receive quality care that the patient needs. Motivation, passion for caring, service delivery, knowledge skills, attitude, behaviour, code of conduct, team player – this is what we have now.*
- *Generally women are in a fragile state of mind when they come for surgery so meeting the Breast Care Nurse gives them a familiar face to relate to pre and post surgery.*
- *A Breast Care Nurse possesses specialised knowledge. Treatment regimes may be very varied and with frequent changing of junior staff and important feature of ongoing care may be missed or delayed without the services of a Breast Care Nurse.*

Q11. Do you think having a Breast Care Nurse available has improved communication between clinical staff about individual patients?

Stakeholders were emphatic that the Breast Care Nurse had improved communication between clinical staff and patients (Table 33).

Table 33. Value of the Breast Care Nurse in improving communication

	Nursing Officer	Medical Officer	Other
Yes	11	3	2
No			
Unsure			
Cannot comment	2		

- *Breast Care Nurse provides the link between the breast care and multidisciplinary team meetings, oncology/surgical meetings.*
- *Sharing information helps both parties in regards to ongoing care of the patient.*

Q12. Do you think that the Breast Care Nurse has improved referral linkages to allied health, mental health or support services?

All respondents considered that the Breast Care Nurse had improved the referral process (Table 34).

- *Breast Care Nurse very aware of what patients need.*
- *Is able to see the whole picture in care path.*
- *The Breast Care Nurse has a broader overview of each woman's management pathway.*
- *Organises echoes etc for patients, provides support for wig services, financial information and travel information etc. Liaisons with oncologist for referral to allied health and support services.*
- *Support services: women who may be reluctant or unable to access Queensland Cancer Foundation are alerted to supports available, e.g. wigs hairdresser. Breast Care Nurse can increase likelihood of rural women keeping to follow-up regimes, e.g. by "clustering" appointments.*

Table 34. Value of the Breast Care Nurse in improving referral practices

	Nursing Officer	Medical Officer	Other
Yes	12	3	1
No			
Unsure			1
Cannot comment	1		

Q13. How successful do you think the project has been in improving service coordination and continuity of care for women with breast cancer?

Service coordination and continuity of care were both seen to have improved because of the project (Table 35).

- *Greater awareness; needs to be supported to continue.*

- *There is no question about the Breast Care Nurse not improving services to patients.*
- *Not much involved in details but I am a strong supporter of Breast Care Nurse as active team member for the Breast Cancer patients.*
- *Part of the success is due to the intelligent care and wide knowledge of the Breast Care Nurse.*

Table 35. Success of the project in improving service coordination and continuity of care

	Nursing Officer	Medical Officer	Other
Very successful	10	1	1
Successful	2	1	1
Somewhat successful			
Unsuccessful			

Q14. Were there barriers that prevented the project meeting its aims?

Aim 1. All women diagnosed with breast cancer in the public sector will be managed by a dedicated multidisciplinary care team.

Although all but one stakeholder noted that the Breast Care Nurses participated in multidisciplinary team meetings (Question 4), concern was expressed by two respondents that formal meetings did not occur (Table 36).

- *Not one multidisciplinary care team meeting. Still disjointed.*
- *I feel creating a formal multidisciplinary care team meeting will greatly facilitate this and is essential. However I do not see this meeting exists.*

One person noted a barrier to referral

- *There was some hesitation from the system to automatic refer on to the Breast Care Nurse. This was probably due to a lack of understanding of the role.*

Table 36. Barriers to meeting Aim 1

	Nursing Officer	Medical Officer	Other
Yes there were barriers	2		1
No there were no barriers	1	1	
Unsure	6	2	1
Cannot comment	4		

Aim 2. All women being treated for breast cancer by Toowoomba Health Services will receive a coordinated approach to their management and treatment including supportive care and access to allied health services.

The person who noted a hesitation in referral to the previous question ticked the box stating that there were barriers (Table 37).

- *As above, as well as possible ownership of the patients.*

One respondent noted there were barriers but didn't say what they were while two stakeholders although not stating that there were barriers commented that red tape was a concern

- *Providing the services to breast care patients when they need the services without long waiting time – less red tape.*
- *As long as adequate staff and financial support is made available all the time and less red tape to get the people the services they need.*

A Nursing Officer considered that distance to services could be problematic.

- *Geographic location may make access to some of the services impossible.*

Table 37. Barriers to meeting Aim 2

	Nursing Officer	Medical Officer	Other
Yes there were barriers	1		1
No there were no barriers	6	1	
Unsure	2	2	
Cannot comment	2		1

Aim 3. All women diagnosed with breast cancer and their families will receive adequate and appropriate information about their treatment, supportive care and financial support for travel and accommodation.

No barriers were identified to prevent Aim 3 (Table 38).

Table 38. Barriers to meeting Aim 3

	Nursing Officer	Medical Officer	Other
Yes there were barriers			
No there were no barriers	7		1
Unsure	2	1	1
Cannot comment	3	2	

Aim 4. Women requiring specialised support for clinical depression, anxiety or other problems will be identified and referred to appropriate services.

No barriers were identified to prevent Aim 4 (Table 39).

Table 39. Barriers to meeting Aim 4

	Nursing Officer	Medical Officer	Other
Yes there were barriers			
No there were no barriers	5	1	1
Unsure	3	1	1
Cannot comment	3	1	

Q15. What specific factors have assisted this project in the achievement of its stated aims?

Respondents identified the work ethic of the Breast Care Nurse and other team members as being instrumental in the success of the project.

- *Hard work by people involved and commitment.*
- *Outstanding dedication and calibre of the Breast Care Nurse.*
- *Person in this role is organised and highly qualified.*
- *Breast Care Nurse has provided breast cancer patients with vital support and has above and beyond the usual duty provided by other Breast Care Nurses.*
- *The Breast Care Nurse contributed significantly to achieving the aims of the program.*
- *Apparently no interferences with Breast Care Nurse's job description. She is the right person.*
- *By the provision of a full time Breast Care Nurse thus assisting in ensuring that patients don't fall through the gaps and therefore being available when patients and stake holders attempt to contact (not having to call on specific days i.e. Tuesdays between 9 and 3 etc.).*

There was also considered to be an acceptance by management of the role.

- *And a notable acceptance by some levels of management at Toowoomba Health Services of the importance of the role that was not evident when it was last trialled.*

Q16. Are there any other comments you would like to make about the impact of the Breast Care Nurse or the project as a whole?

Nursing Officers offered other comments supporting the project and one hoped that a similar model could be used in other areas.

- *I have always found the Breast Care Nurse very helpful when patients have had queries that I have not been sure how to answer. Breast Care Nurse has reviewed patient and answered her and my concerns; both pre and post operatively.*
- *Hope we have a full time Breast Care Nurse and it is fully supported by Queensland Health.*
- *Having access to the Breast Care Nurse on a full time basis has been the best step forward that this health service has taken. Women have really appreciated the support.*
- *My impression is that it has been a positive project with positive management.*
- *The role of the Breast Care Nurse has improved the treatment outcomes for clients. My role as a nurse in the clinical setting has been made easier by liaising with the Breast Care Nurse to ensure optimal outcomes for my clients.*

- *Well done Breast Care Nurse and project team! All patients' families and significant others benefit from the Breast Care Nurse.*
- *The Breast Care Nurse is excellent in this role. It would be a shame for women who access this service to lose this expertise.*
- *The role of the Breast Care Nurse on a full time basis is vitally important to adequately support women with cancer. The best thing that this hospital has ever done. The number of women who access this hospital for surgery is gaining enormously – servicing a large area of Southern Queensland. It would be remiss of this service not to have a full time Breast Care Nurse.*

The community organisation representative recognised the importance of the position and also having the correct person in that position.

- *Having experienced the role when it was last trialled at a 0.5 position and the lack of access during that for patients, clinicians and stakeholders it was a pleasure during this project. Knowing that the patients had ready access as did clinicians and stake holders as simply as a phone call. It is also important that the Breast Care Nurse not only have the clinical skills but the ability to perform the role not only for the patients but also perform as a member of a multidisciplinary team.*

Two respondents indicated that outside the immediate project knowledge of the Breast Care Nurse was poor.

- *General RNs don't know all the support services that are available.*
- *Needs to be made clear to all staff as to what has been done.*

Finally, one of the Medical Officers considered that the role could expand

- *It could be that the Breast Care Nurse could need an assistant/colleague in the not too distant future.*

Discussion

A limitation to the study is that it did not offer an opportunity to interview women who had not received any support at all. Not only would it have been interesting to determine how they perceived their needs had been met but it would have offered a better determination of the role of the Breast Care Nurse.

A further limitation is that all but 12 women who were interviewed had contact with only one Breast Care Nurse. Of the 12 who had contact with a prior Breast Care Nurse that contact was infrequent and not as detailed as that offered after July 2005 when the position became full-time. A true comparison in delivery of service by different practitioners therefore cannot be made. The consequence of this is that it is very difficult to remove the influence of the personality of the incumbent. In fact it was very noticeable that the vast majority of the women who were interviewed were unable to dissociate the role in general from the role as performed by the incumbent.

The observation of the research team is that the incumbent is a highly personable, highly motivated and dedicated professional. It is apparent that she is loved and respected by patients and team members alike. Her personal attributes in no small way contribute to the success of the programme. Another study also noted that they were not able to differentiate between the role and the incumbent to that role²³.

These limitations do not detract from the overall value of the evaluation. Nor do they reduce the primary conclusion of the study that the vast majority of the women's experiences during their breast cancer treatments had been made positive because of the support they received from the Breast Care Nurse. What was potentially a major life trauma was made manageable by the support offered by the Breast Care Nurse (and others within the system) at any time they needed it.

The model of care offered by the Breast Care Nurse project is one that could be mirrored for other illnesses and this was mentioned by one stakeholder who noted:

May other tumour streams have the money and health service direction, support and energy to provide similar services in the near future.

The evaluation team also recognised the number of positive comments made by participants about the staff of Toowoomba Base Hospital and in particular that of the BreastScreen Queensland Clinic.

Two thirds of the women found out about the Breast Care Nurse and the services provided at the first contact with the nurse herself. The next highest source of knowledge was noted as being at the BreastScreen clinic. However it is possible that for the latter information was in fact given by the Breast Care Nurse herself as some women at that time assumed she was just a member of BreastScreen staff and not aware of the dedicated role.

Although one could argue that the service is only relevant after diagnosis, we suggest that given that the high profile of breast cancer and importance and benefits of this service that little prior knowledge existed is surprising. Certainly family doctors do not seem to be providing this information. In contrast to our finding, a study in Bendigo noted that information about the programme was provided by GPs and family contacts as well as nursing staff, surgeons and BreastScreen²³. One reason could be that there are many more Breast Care Nurses in Victoria. It is not known

whether the general practitioners in our study, many of whom may only see one or two cases per year, are themselves fully informed about the Breast Care Nurse.

From additional information offered by the women there appears to be a difference in women's initial contact with the Breast Care Nurse according to whether they receive a call-back following a routine mammogram or whether the lump was self-detected. If they were called back by the staff of BreastScreen following a mammogram, then the Breast Care Nurse invariably introduced herself at the assessment clinic and was in regular contact from then on. However if the lump was discovered by themselves and they were referred by a GP, their first encounter with the Breast Care Nurse was more likely to be in the hospital at the time of meeting with the surgeon. Nevertheless the vast majority of the participants agreed that the timing of the first contact was at the right time.

Contact with the Breast Care Nurse was easy. The value of the full-time position of the Breast Care Nurse is evident here. Reduction of this position to less than full-time would only be effective if it was incorporated into another role that was similar in terms of physical presence of the Breast Care Nurse. It is worthy of note however that 65% of women would have preferred to make their own appointment times.

Much of the questionnaire was devoted to the perception of the amount of information that was provided and the timing of that information. The timing of consultations and the time for consultations were both considered appropriate. Several women recognised that they were given a considerable amount of information and the Breast Care Nurse was invaluable in helping them understand it. It may be speculated that had the Breast Care Nurse not been available, difficulties and confusion may have resulted.

Almost without exception, the participants of the evaluation agreed that accessing a hospital with a dedicated Breast Care Nurse was the preferable option. They also considered having the same Breast Care Nurse would be advantageous however it should be remembered that the vast majority only had the experience of one Breast Care Nurse.

Coordination of care and information needs were also considered to have been met as were psychosocial, emotional and practical support needs. The Breast Care Nurse was seen as someone who had the time to be able to offer these functions. One of the services offered by the Breast Care Nurse was advice about who else to talk to. The data showed that referrals to other professionals were done to varying degrees. Sometime referrals were not relevant, for example referral to a chemotherapy nurse was not offered if chemotherapy was not a treatment. In other cases referrals would not have been made because no such service existed in the home location of the client.

Those who did not require much support could still relate to the difference a Breast Care Nurse might make. Those requiring high support particularly of an emotion nature, commented that a potential life trauma was made manageable by the support offered at any time they needed it. The support provided was highly individualised and may have been emotional, practical or tacit in any combination. Support was described as comforting and offering security. The knowledge that there was support available was often enough in itself and even people who handled the experience well and did not access the service very much were highly supportive.

You do feel a bit alone and having support [of the Breast Care nurse] gives you strength and courage - someone understands ... somebody gave a damn whether you lived or died within a system

Feedback from stakeholders also was very positive. They recognised the role of the Breast Care Nurse in providing information, support and acting as a liaison among members of the team.

There were only a couple of areas in which negative comments were offered. The first was the observation that awareness of the programme was limited to those directly involved and other staff were unaware of the support service. One respondent suggested that this lack of knowledge could disadvantage women as they may not be informed of the service and seek support elsewhere.

The other negative comments were in response to the question asking about barriers to successful operation of a multidisciplinary team. In several cases the desire for this approach was recognised but the absence of a genuine approach with meetings was noted.

The true value of the Breast Care Nurse project requires further study. A comparison with outcomes and quality of life of other breast cancer patients who have not benefited from contact is needed.

Most notable however is the omission in studies (this one included) that determine the success of the programme in terms of financial benefits. Consequently arguments on whether to keep or modify what is clearly a successful activity are based on actual costs of the Breast Care Nurse against views and perceptions of patients and stakeholders.

Comparing actual costs with attitudes provides a relatively easy argument for diverting funds to other programmes. What is missing for proponents of the Breast Care Nurse strategy are figures related to the savings to the health service which may be used in arguments to support the programme. These include savings in the direct cost of breast cancer patients' health care. We suggest that as a result of the Breast Care Nurse interventions, there is a reduction in additional management post surgery, for example as a result of infections. Furthermore fewer women would need psychological support as a result of counselling by the Breast Care Nurse. Of the 52 women interviewed for this study not one noted that they required additional psychological support to that offered by the Breast Care Nurse.

Not only is the information and support offered by the Breast Care Nurse likely to reduce the direct health costs for the breast cancer patients, but health professionals will be able to realise time savings which may be put to benefit of other patients. Only when these costs are quantified will the true benefit of the programme be realised.

Conclusions

Virtually all of the results collected in the study demonstrated that the Breast Care Nurse position was considered to be a great value by the consumers. Respondents expressed concern about the future if funding was withdrawn and the Breast Care Nurse was not maintained. The Breast Care Nurse offers valuable information, support and advice and is instrumental in ensuring that there is continuity of care. There is a clear recommendation from consumers and stakeholders alike for continuation of the programme. These conclusions mirror those of studies that have been undertaken in Australia^{15,17,19,22,23,25}. Additional study is recommended to determine the actual savings to the health system as a result of the Breast Care Nurse programme.

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Appendix 1. Breast Cancer Patient Questionnaire

Interviewer administered survey

Participant ID Number _____

1. First contact with BCN

Before July 2005		July 2005 onwards	
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1a End of Treatment

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2. Surgery and treatment regimen (tick all that apply)

Surgery	
Chemotherapy	
Radiotherapy	
Other treatment (e.g. hormonal)	

A. Awareness of Breast Care Nurse

3. How did you find out about the BCN? From: (tick as many boxes as applicable)

Private surgeon	
Hospital doctor/nurse	
Staff at BreastScreen	
Your GP	
The Breast Care Nurse introduced herself	
A Breast Cancer Support Service volunteer	
Friend or family member	
Other (please specify).....	

4. Who explained the role of the BCN to you? (tick as many boxes as applicable)

Nobody	
Breast Care Nurse	
Private surgeon	
Hospital doctor/nurse	
Staff at BreastScreen	
Your GP	
A Breast Cancer Support Service volunteer	
Friend or family member	
Other (please specify).....	

5. When was your first contact with the BCN? (tick one box only)

At diagnosis or within a couple of days after this	
During the time leading up to your surgery	
After your surgery but before you were discharged home	
When you returned home from hospital	
At your first follow-up visit with the hospital staff/doctor	
Other (please specify).....	

6. How do you feel about the timing of your first contact with the BCN (tick one box only)

	Far too early	A little early	At the right time	A little late	Far too late
Was the contact					

B. Access to Breast Care Nurse

7. Was enough time generally made available during the consultations? (tick one box only)

	Very short	Short	Just about right	Too long	Much too long
The time was					

8. Were you able to contact the Breast Care Nurse whenever you wanted to? (tick one box only)

	Very difficult	Difficult	Just about right	Easy	Very easy
Contacting the BCN was					

9. How would you have preferred your appointments with the Breast Care Nurse? (tick one box only)

	Regular	When I wanted them	As set up by BCN
Preferred appointment method			

10. How satisfied were you with how the consultations fitted with your treatment? (tick one box only)

	Well timed	Some could have been better timed	Badly timed
The consultations were			

11. How satisfied were you with your level of contact with the Breast Care Nurse? (tick one box only)

	Far too little	Too little	Just about right	Too much	Far too much
The level of contact was					

- 12. Do you think having the same Breast Care Nurse as a contact person during your treatment was of any benefit? (tick one box only)**

	Unsure	No benefit	Yes, a little benefit	Yes, of great benefit
Benefit of having the same BCN				

C. Coordinating care

- 13. How would you rate the amount of help from the Breast Care Nurse on the following: (tick one box only for each statement)**

	Wanted more	Right amount	Wanted less	N/A
Understanding the roles of the different people involved in your treatment				
Understanding the information you received from different doctors and health workers				
Communicating your needs to other health workers				
Making appointments for you				
Making the transition to the next stage of your treatment easy				

D. Information Needs

- 14. How would you rate the amount of information you received from the Breast Care Nurse about the following: (tick one box only for each statement)**

	Wanted more	Right amount	Wanted less	N/A
Your cancer				
Your treatment choices				
The treatment itself				
Side effects of the treatment				
Caring for yourself at home				
Support services (e.g. support groups, Breast Cancer Support Service, Cancer Information Service)				

15. Do you believe that the Breast Care Nurse (tick one box only for each statement)

	<i>Strongly Agree</i>	<i>Agree</i>	<i>Disagree</i>	<i>Strongly Disagree</i>	<i>N/A</i>
Allowed you to share your real feelings with her					
Was good at explaining things					
Gave you too much information					
Said things that helped you cope or feel a little better about things					
Offered advice, practical support, or information at the times when you most needed them					
Offered sufficient information of where to seek spiritual support					
Was open to discuss alternative therapies with you					

E. Psychosocial support

16. Having contact with the Breast Care Nurse has helped: (tick one box only for each statement)

	<i>Strongly Agree</i>	<i>Agree</i>	<i>Disagree</i>	<i>Strongly Disagree</i>	<i>N/A</i>
You to deal with your diagnosis					
You make choices about treatment					
You with relationship or communication with your doctor					
You deal with concerns your family had about your cancer					
You express and manage your feelings about the cancer					
You deal with side effects					

F. Emotional Support

17. How satisfied were you with the emotional support from the Breast Care Nurse: (tick one box only for each statement)

	Very Satisfied	Satisfied	Not Satisfied	Very Dissatisfied	<i>N/A</i>
Before treatment					
During treatment					
After treatment was finished					

G. Practical Support

18. Did the breast nurse provide you with enough help in the following? (tick one box only for each statement)

	Not enough	About right	Too much	N/A
Offering information re travel and/or accommodation				
Getting a prosthesis				
Understanding how long I would be in hospital				
Understanding what would happen when I was discharged				

H. General effect seeing a breast nurse had on you.

19. In advising a friend about getting treatment for breast cancer, would you say: (tick one box only for each statement)

	Yes	No	Don't know
Only choose a hospital which provides a Breast Care Nurse			
Prefer a hospital with access to a Breast Care Nurse			
Don't worry about whether a Breast Care Nurse is available at the hospital			

I. Referral

20. Did the Breast Care Nurse suggest or offer you the chance to talk to any of the following groups of people? (tick one box only for each statement)

	Yes	No	Don't Know	Not Applicable
A social worker or welfare worker				
A psychologist				
A Breast Cancer Support Service volunteer				
The Queensland Breast Cancer Fund Service				
A Breast Cancer Support Group				
A physiotherapist				
A chemotherapy nurse				
Your GP				
Community nurse				

J. Other

21. Do you have any other comments?

.....

.....

.....

Appendix 2. Plain Language Statement and Consent Form

TOOWOOMBA HEALTH SERVICES BREAST CANCER SUPPORT SERVICE EVALUATION

Conducted by Centre for Rural and Remote Area Health (CRRAH)
UNIVERSITY OF SOUTHERN QUEENSLAND

INFORMATION SHEET AND CONSENT FORM

RESEARCHERS:

- **Dr Rob Eley**, Senior Research Fellow, CRRAH, University of Southern Queensland, Telephone: 4631 5477. Email: eleyr@usq.edu.au
- **Dr Cath Rogers-Clark**, Head, Department of Nursing and Midwifery, University of Southern Queensland, Telephone: 4631 2005. Email: rogerscl@usq.edu.au
- **Ms Christine Knight**, Project Officer, CRRAH, University of Southern Queensland, Telephone: 4631 1992. Email: knight@usq.edu.au

The project and your requested involvement:

This project aims to evaluate the Breast Cancer Support Service offered by Toowoomba Health Service, which has involved the employment of a Breast Care Nurse to provide support and continuity of care to women with breast cancer.

The researchers would like to invite you to be interviewed by telephone about your experience as a patient of the Breast Cancer Support Service. This would involve answering a number of questions about different aspects of the service, and your use of it, and would take about 15 minutes to complete, at a time of your choosing. The interviewer, Christine Knight, is an experienced and supportive professional health worker who is employed by CRRAH and has no relationship to Toowoomba Health Services.

Your involvement will help in future development of the service.

Voluntary participation:

Your participation in this project is voluntary. If you do agree to participate, you can withdraw at any time without comment or penalty. Your decision to participate will in no way impact on your current or future care at Toowoomba Health Services or any other Queensland Health facility.

Confidentiality:

The information you provide will be recorded anonymously and treated confidentially. Toowoomba Health Services will only have access to a report which summarises the data collected from all participants. Your individual comments about the service will not be made available to Toowoomba Health Services.

Questions/concerns/complaints:

If you have any questions please contact any of the researchers named above. If you have a concern regarding the implementation of the project, you should contact The Secretary, Human Research Ethics Committee USQ or telephone (07) 4631 2956.

**TOOWOOMBA HEALTH SERVICES BREAST CANCER SUPPORT SERVICE
EVALUATION**

PARTICIPANT CONSENT (Patient Group)

Statement of consent:

I agree to participate in the Breast Cancer Support Service Evaluation, which will involve one telephone interview of approximately 15 minutes duration. I have read and understood the information provided to me about this project, and have had my questions about the project answered to my satisfaction. I understand that the information I provide will remain confidential, with only summarised data presented in the final report. In signing this consent I realise that I have the right to withdraw from this study at any time.

Name: _____

Signature: _____

Date: _____

Witness: _____

Date: _____

Please return this form to CRRRAH in the attached reply paid envelope

Appendix 3. Breast Cancer Stakeholder Questionnaire

Supporting Rural Women with Breast Cancer Questionnaire

Background

The Toowoomba based Supporting Rural Women with Breast Cancer Project has been managed by Cancer Screening Services Unit, Queensland Health since January 2005. The aim of the project is to develop & implement a revised multidisciplinary model of care resulting in the reorganisation & enhanced coordination of breast care services provided by Toowoomba Health Service District. A central role in the project in providing supportive care is the Specialist Breast Care Nurse (BCN).

Aims of Project

- All women diagnosed with breast cancer in the public sector will be managed by a dedicated multidisciplinary care team.
- All women being treated for breast cancer by Toowoomba Health Services will receive a coordinated approach to their management and treatment including supportive care and access to allied health services.
- All women diagnosed with breast cancer and their families will receive adequate and appropriate information about their treatment, supportive care and financial support for travel and accommodation.
- Women requiring specialised support for clinical depression, anxiety or other problems will be identified and referred to appropriate services.

Evaluation

A key deliverable under the service agreement with the Australian Government is the implementation of an evaluation plan and the compilation of an evaluation report. Evaluation is being undertaken of women who have been supported by the breast care nurse and of key stakeholders and health professionals. The evaluation is being undertaken by the Centre for Rural and Remote Area Health (CRRAH), a joint centre of University of Southern Queensland and University of Queensland based at USQ Toowoomba.

No personal details are requested on this questionnaire but you will note that we do ask you to nominate your area of work so it is possible that your identity could be deduced from that. However, only the researchers (Rob Eley, Cath Rogers-Clark and Christine Knight) will see your completed questionnaire which will be kept confidentially at CRRAH. Your individual responses will not be released by the research team; the data provided by respondents will be aggregated before the evaluation report is written to ensure your confidentiality.

If you would prefer to answer the questionnaire during a telephone interview please call either Ms. Christine Knight on 4631 1992 or Dr. Rob Eley on 4631 5477. In this instance your name and any contact details will be destroyed after the interview to ensure your privacy.

Supporting Rural Women with Breast Cancer Questionnaire

Please indicate your area of work

Area	
Aboriginal Health	
Cancer Care Service	
Community Health	
Day hospital	
Day Oncology	
Director Medical Unit	
Director of Nursing	
Discharge planning	
General Practice	
Infection Control	
Medical Imaging	
Medical Outpatients	
Nurses in Breast Clinic	
BCN in private hospital	
Pathology	
Physiotherapy	
Preadmission	
Pre-anaesthetic Clinic	
Private Practice	
Queensland Cancer Fund	
Surgical Outpatients	
Surgical Unit	
Theatre bookings	
Other (please specify)	

Please indicate your profession

Nursing officer	
Medical officer	
Professional officer	
Administrative officer	
Other (please specify)	

1. How would you describe your awareness of the role of the Breast Care Nurse (BCN)

Very aware	
Aware	
Unclear	
Unaware	

2. On average, how often have you been in contact with the BCN?

Several times a week	
Weekly	
Fortnightly	
Monthly	
Less than monthly	

3. What do you see as the particular role of the BCN within the treatment team?

.....

.....

.....

.....

.....

4. Did the BCN participate in multidisciplinary team meetings, case discussions or reviews?

Yes	
No	
Unsure	
Not in a position to comment	

5. In your view was the BCN able to influence clinical/case management decisions for individual clients?

Yes	
No	
Unsure	
Not in a position to comment	

If not, why not?.....

.....

.....

6. Would you say her input was valued by clinical and nursing staff?

Yes	
No	
Unsure	
Not in a position to comment	

If not, why not?.....
.....
.....
.....
.....

7. Do you feel that members of the treatment team have made appropriate referrals to the BCN?

Yes	
No	
Unsure	
Not in a position to comment	

If not, why not?.....
.....
.....
.....
.....

8. Did you or any of your patients encounter any difficulties accessing the BCN?

Yes	
No	
Unsure	
Not in a position to comment	

If yes, comment
.....
.....
.....
.....
.....

9. Thinking about the BCN role, what if any changes could be made to improve patient outcome?

Yes	
No	
Unsure	
Not in a position to comment	

If yes, please indicate what these changes could be and why?

10. Do you feel that a BCN is important for ensuring women receive high quality care?

Yes	
No	
Unsure	
Not in a position to comment	

Comment.....

11. Do you think having a BCN available has improved communication between clinical staff about individual patients?

Yes	
No	
Unsure	
Not in a position to comment	

Comment

12. Do you think that the BCN has improved referral linkages to allied health, mental health or support services?

Yes	
No	
Unsure	
Not in a position to comment	

If yes, in what way?

.....

.....

.....

13. How successful do you think the project has been in improving service coordination and continuity of care for women with breast cancer?

Very successful	
Successful	
Somewhat successful	
Unsuccessful	

Comment

.....

.....

.....

.....

14. Were there any barriers that prevented the project meeting its aims:

Aim 1. All women diagnosed with breast cancer in the public sector will be managed by a dedicated multidisciplinary care team.

Yes there were barriers	
No there were no barriers	
Unsure	
Not in a position to comment	

If yes, in what way?

.....

.....

.....

Aim 2. All women being treated for breast cancer by Toowoomba Health Services will receive a coordinated approach to their management and treatment including supportive care and access to allied health services.

Yes there were barriers	
No there were no barriers	
Unsure	
Not in a position to comment	

If yes, in what way?

.....

.....

.....

Aim 3. All women diagnosed with breast cancer and their families will receive adequate and appropriate information about their treatment, supportive care and financial support for travel and accommodation.

Yes there were barriers	
No there were no barriers	
Unsure	
Not in a position to comment	

If yes, in what way?

.....

.....

.....

Aim 4. Women requiring specialised support for clinical depression, anxiety or other problems will be identified and referred to appropriate services.

Yes there were barriers	
No there were no barriers	
Unsure	
Not in a position to comment	

If yes, in what way?

.....

.....

.....

15. What specific factors have assisted this project in the achievement of its stated aims?

.....
.....
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.....

16. Are there any other comments you would like to make about the impact of the BCN or the project as a whole?

.....
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.....

Thank you for your time in completing this questionnaire.

Please return the attached questionnaire by one of the following methods.

- a) return the printed form to CRRRAH in the reply paid envelope
- b) return an electronic version of the form to eleyn@usq.edu.au
- c) fax the form to CRRRAH at 4631 5452

Appendix 4. Comments

Queensland Health staff and service in general	Breast Care Nurse role and position	Specific practical support offered by BCN	Personality of the current BCN
Very, very happy with staff at Toowoomba Base. I find the people very nice to speak to and easy to get on with.			
	I didn't appreciate BCN at beginning because didn't realise how much you would need her later - if I had known that then I would have appreciated her much more. Until you have gone through it - don't realise how much benefit having someone who is always there for you. More secure comforting. Now cannot imagine getting through it without her.	So many questions small and big - can always ring her.	
	My husband and I couldn't have gotten through this without [BCN] especially my husband - not much out there for him - she is always there.		
All the girls are wonderful there in the Breast clinic.	Would just like to say how fortunate I was to have access to BCN all the way through. She answered everything and was so supportive. She is still available even though it's eighteen months on. I don't know how I and my family would have coped without her.		She is now a good friend.
	I reckon they should keep the Breast Care Nurse. I thought surgery would be a 'cure' until the GP explained that they 'look after you' for 5 years.	[BCN] explained everything - a big shock and absorbing information was hard.	

Queensland Health staff and service in general	Breast Care Nurse role and position	Specific practical support offered by BCN	Personality of the current BCN
	She is worth her weight in gold - BCN is great idea and great help.		
I had lovely treatment at the hospital.	The breast care nurse was absolutely marvellous. Hope and pray that they never do away with them. They are really and truly needed. The one on one is excellent.		
			She was very good, very helpful.
	BCN was waiting in Brisbane at the Mater - makes a big difference because my family couldn't be with me.		She's doing a wonderful job.
	The service is invaluable – needs a female BCN to communicate with. It is really important having access to the BCN at any time – means you are not isolated, you have a lifeline. Comforting to know there is a BCN at the Mater as well.	Information she gives is clear – not pussy footing – medical but not over your head.	
	Would have died without her – literally. I completely crashed and went to pieces. The BCN, psychiatrist and social worker provided intensive support for six months. BCN still looking after me for PTSD after my chemo.		
The Nursing Sister at Dalby Clinic was wonderful and supportive as well – especially the three months before my first surgery. I had the second operation at Dalby hospital too and they did a very good job. The BCN and other nurses do a wonderful job.		You do need a lot of information and she helped me understand it.	

Queensland Health staff and service in general	Breast Care Nurse role and position	Specific practical support offered by BCN	Personality of the current BCN
	It is a valuable thing - a BCN in Toowoomba and at the Mater in Brisbane. BCN explained things well to my daughter.	Need to find some information for younger children like my daughter 12 year old.	Toowoomba one is much better (than Mater). [She] is fantastic.
	I waited seven or eight 8 hours for surgery by myself. BCN is a good idea but need more than one to enable contact to everyone.	I did it all by myself. Another woman from a remote area and I support each other by phone.	
	Wouldn't have coped without her. Her support was invaluable.		
	BCN sat with me all morning while waiting for surgery.		
	...if you didn't want to talk to her she didn't hang around - she knew. Very responsive BCN is a good thing - there if you needed her She is still there if I need her - very comforting.	She helped me to understand the information given.	Thought she was marvellous.
			I have only talked to her once or twice since (treatment finished) – to let her know how I was going She did a marvellous job - don't know where I would have been without her. She was brilliant.
BreastScreen was great.	Treatment ended prior to BCN commencing It was of no benefit to me but I can imagine it would be good for others.		
All hospital staff lovely at Toowoomba Base.			
	Would have liked to have had someone to talk to between diagnosis and seeing surgeon about surgery.		

Queensland Health staff and service in general	Breast Care Nurse role and position	Specific practical support offered by BCN	Personality of the current BCN
I found them [Toowoomba Hospital] very good in anything I needed.		So much information Thank goodness someone explained it - aboriginal people don't understand this stuff - they were very good with me.	
	Toowoomba needs two BCN's - she is flat out and does a great job. You can't talk to your doctor this way mine's male and hasn't got time.		
They were all wonderful supportive and helpful [at BreastScreen].			
So impressed with BreastScreen - would recommend Qld Health to anyone Very positive experience.			
	She is a much needed link - someone you know to guide you through.		
	Very grateful she was there. She is very sensitive and caring. Her number is by the phone.		
Toowoomba Hospital was great. I was so grateful I made a patchwork piece as a gift to the breast clinic.	I was really blown away by the fact that she was there if you needed her - she is essential because you need practical and emotional care.		
	Would be a very big shame to lose (BCN) - for past and future patients - we really do need one Made a huge difference especially with the complications I've had.		
	I think she was pretty good.		
	I would have been devastated - BCN made it a positive experience.		She's definitely irreplaceable - get her to train any other BCNs that are hired.
	Her services are invaluable. Two years on and she is still a link if I need it.		

Queensland Health staff and service in general	Breast Care Nurse role and position	Specific practical support offered by BCN	Personality of the current BCN
	I think they are necessary - she was there every step of the way. She was more approachable than the doctor because of her role.		
Extremely happy with everyone at Toowoomba Base and the Mater.	She was there the whole time for me, even after treatments.		Got to know her better - more like a friend than somebody just doing their job.
The public system never once let me down - I can't fault it.	I can't emphasise strongly enough how essential they are to the treatment and ongoing care.		I rely quite heavily on her actually.
I have been treated really well at Toowoomba Base – great. I highly commend the services - they were very, very good - the bus group were great.	[A substitute filled] in for BCN while she was on holiday. Sub was great, she sat with me after surgery.		
	She always had time to talk to you (by phone in this case) She rang on the speaker phone and spoke to the whole family.		
A very positive experience. The whole hospital was wonderful. They do a mighty job and it wouldn't be easy.	I felt very comfortable with BCN. You do feel a bit alone and having support such as the BCN gives you strength and courage - someone understands.		
All the nurses are absolutely marvellous -	I found it invaluable - somebody gave a damn whether you lived or died within a system - nothing was too much trouble for her and still isn't.		
	I wouldn't have made it without the BCN. She was there when I went to see the surgeon. I put a lot of my wellness down to BCN's help.	Doctors are so busy and they don't have the time to explain things.	

Queensland Health staff and service in general	Breast Care Nurse role and position	Specific practical support offered by BCN	Personality of the current BCN
	There should be BCN in every hospital that does the surgery – it is imperative. I couldn't believe that other hospitals don't have one.		She is wonderful They all need to be as caring as her - a friend as well as a BCN.
She does a mighty job. I couldn't speak highly enough about the hospital and the chemotherapy unit.			
	It was a lot better with a BCN this time. BCN had time off and another person filled in for her - I got an infection after surgery and was put back in for 9 days - substitute BCN visited me every day - was great to have a friendly face to talk to.		BCN was a very nice lady - one of the best you could have in the job.
BreastScreen ladies provide great emotional support.	I found the service lovely. Get another BCN if you can.		
Everyone in BreastScreen was supportive – I didn't miss what I didn't know about.			
	I think it is an essential position to be maintained.		