

Caring for me?

***Final report of the development of a tool
for consumer feedback on hospital
breast services in Victoria***

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1 Introduction

One of the key action areas for the Department of Human Services' Breast Disease Service Redevelopment Strategy 1999-2003¹ was the development of a measurement tool and process for reporting on the acceptability to consumers of the quality of the service they received.

Following some initial work by Dr Delwyn Goodrick, in July 2003 BreastScreen Victoria was commissioned by the BreastCare Coordination Unit, (now the Cancer and Palliative Care Unit) Victorian Department of Human Services to develop a consumer feedback toolkit for use by Victorian public hospital breast services. The purpose of this toolkit was to elicit consumer feedback to encourage quality improvement at a local level.

Gauging meaningful consumer feedback is a challenging task in two key ways. Firstly, in developing ways to capture feedback that truly reflects the consumer's expectations and experience. Secondly in generating feedback from that process that is meaningful, useful and valued by service providers and, most importantly, that facilitates identification of specific areas for improvement. Given these challenges, the project developed in an evolutionary manner as we grappled with those challenges to develop a resource and approach that we hoped would bridge those two areas of need.

This report briefly summarises the initial exploratory work undertaken to inform the Project and the subsequent development of the *Caring for me?* resource. The report then details how the *Caring for me?* resource was taken up and trialled within three breast services in Victoria over a twelve month period in 2005 to early 2006. The results and learnings of the trial further demonstrate the evolutionary nature of developing effective consumer feedback tools. Recommendations to build on this experience are made.

2 Background

2.1 Project aims

In 2003 the overall aims of the project were articulated as:

- To ascertain the current development and use of consumer feedback mechanisms (if any) by Victorian public hospital breast services.
- To identify the issues concerning the development and use of consumer feedback mechanisms more broadly
- To liaise closely with the Breast Services Enhancement Program (1999 -2004) staff and consumers to determine the most appropriate and useful mechanism(s) by which consumer feedback can be collected and utilised to enhance service performance.
- To conduct a small-scale trial of the proposed consumer feedback mechanisms to identify areas for refinement and possible issues in implementation.
- To submit a package of consumer feedback mechanisms to BreastCare Victoria (now the Cancer and Palliative Care Unit).

2.2 Consultation and review

The initial project phase (July 2003 – January 2004) involving stakeholder and consumer consultation and a literature review, focussed on the first three Project aims. The Consumer Reference Group for this process included 13 women, 11 who have experienced breast cancer and who met regularly during the project. The key findings included:

- Consumer input is invaluable in informing efforts to improve the quality of health services.
- Consumers should be actively involved in the development of consumer feedback mechanisms.
- While there were a range of consumer feedback mechanisms in place within Victorian health services at the time, there was inconsistency in how this feedback was obtained across services and more limited evidence of how it was used to inform service improvement.
- Feedback based on consumers' actual experience of a service provides better information for quality improvement than ratings of satisfaction.
- Multiple approaches including complaint mechanisms are needed to capture the different views of a range of consumers.
- Consumer feedback is only useful if it is part of a quality improvement process within a service.

From these findings it was clear that a toolkit providing a range of consumer feedback mechanisms (such as surveys, focus groups, suggestion boxes) and guidance for use should be developed. This toolkit would be built upon consumer values which underpin a series of consumer expectations for the provision of high quality care.

While this initial consultation was being undertaken, BreastScreen Victoria was also being commissioned by the Department of Human Services to undertake a new project which involved an extended trial of a newly developed set of performance indicators², the development of standards for breast services and the modelling of a quality improvement cycle for public hospital breast services. This Project, the Breast Services Performance Indicator and Standards Project³, to be trialled in 2004-05, provided an important opportunity to embed consumer feedback into a broader framework of performance measurement and quality improvement.

It was agreed that once the consumer feedback toolkit was developed, it would be trialled by two of the public hospital breast services participating in the Performance Indicator and Standards Project.

2.3 The Consumer feedback quality loop

During discussions with the Consumer Reference Group around how feedback would ideally be sought and used, a chart was devised to illustrate the process of gathering feedback and its

relationship to quality improvement. The 'Consumer Feedback Quality Loop' arose from a concept proposed by Dr Delwyn Goodrick, a member of the Working Group and is illustrated in Figure 1.

The figure illustrates two key gaps that were identified in this work:

- The need to provide a framework for consumers to assist in reflection on their experience of care – What might I have expected? What did I experience? How do they differ? – this precipitated the development of *Caring for me?*
- At the hospital level, the need to have mechanisms in place by which feedback can be received, reflected upon and used within a broader quality improvement process to identify areas for service improvement. Similarly, the importance of having mechanisms for the inclusion of consumers in that process was acknowledged.

The cycle includes several key points. For consumers, the central question is 'What did I experience while using this service? What would I have liked? If there is a gap – what can I do about it?' The *Caring for me?* booklet sets the context for the patient's reflection on their experience of care.

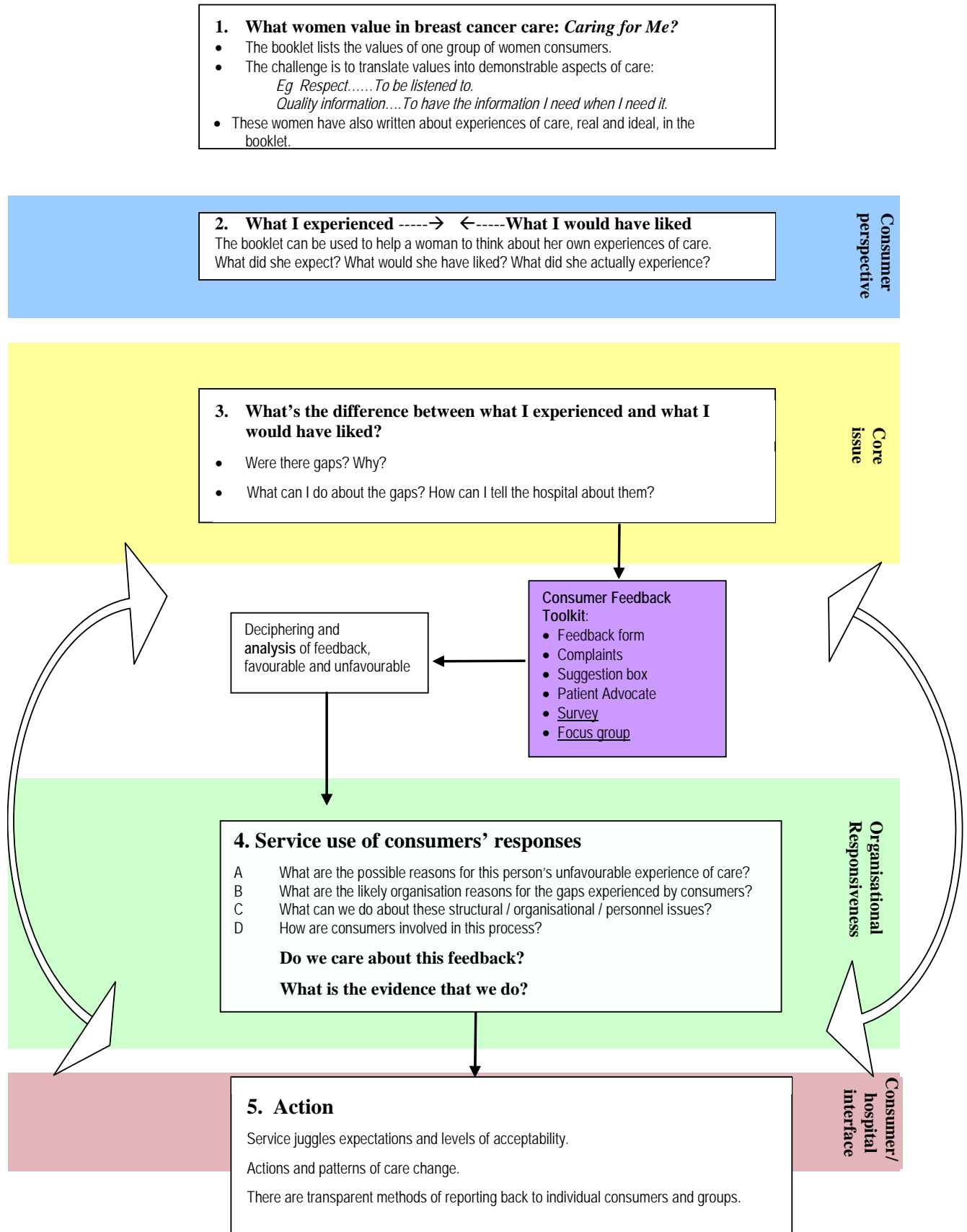
Six potential ways are shown for the women to bring the gap to the service's attention. The less formal ways are using a suggestion box or an open-ended feedback form or card. The more formal are participation in a survey and/or a focus group.

Over an agreed period (e.g. a quarter), a breast service could collect a variety of information from a variety of sources. What is common to this feedback is that it represents women's actual experiences. When analysed, the data is likely to reveal common themes, and in addition, there may be an example of a rare but significant failing.

The second key point in the Quality Loop is the question for the hospital of 'How will it make use of this information to improve its breast service?'

The 'Quality Loop' suggests that hospital personnel and consumers together consider the results and set priorities for action. The results and the subsequent actions are then fed back to the consumers who are direct users of the service, and to interested groups such as the hospital's Community Advisory Committee. The 'Quality Loop' is completed with the use of feedback and the communication to patients about how feedback is used by the hospital to inform improvements in care. This in itself may provide encouragement for consumers to provide feedback.

Figure 1. Consumer feedback quality loop



2.4 Development of *Caring for me?*

The *Caring for me?* resource was seen as the key resource that would reflect the core values that consumers considered should underpin good quality care. The development of the resource occurred after a lengthy process of consultation with the consumer reference group and involved determining the most appropriate way forward and how to how best to capture the issues that are of importance to consumers.

Thirteen consumers participated in two extensive workshops to identify the core consumer values underpinning a quality breast service.

In recognising that every woman would have her own system of values and would come from diverse backgrounds, the group and project staff worked to achieve broad consensus on the core values and to ensure that the language was accessible to a broad audience. Box One highlights the eight agreed core values.

Box one: The agreed core values for quality breast care services

- Being supported to make choices
- Best treatment
- Complete care
- Fairness
- Feeling safe and comfortable
- Good communication
- Personalised care
- Respect and dignity

Quotes and key statements were developed by the consumers based on their experience demonstrating a range of ways in which each area of care may be demonstrated in practice. The following provides an example of how the information was presented for each value.

Respect and dignity

Women talking about respect and dignity.....

'The fears I expressed were taken seriously and reduced by the way I was treated.'

'I felt I was treated as a person rather than just another patient – "the right or left mastectomy".'

How could this have been shown during my care?

- The doctors listened to me and encouraged me to ask questions.
- My personal information and need for privacy was respected.
- I was suitably clothed and the focus was on me (with no distractions) when important things were being discussed.
- I was given an explanation and apology when kept waiting.

The original resource was developed into an A5 booklet as an information resource for women to allow them to reflect upon the care they received against each of these eight dimensions. It also provided information on ways in which they may be asked or may choose to provide feedback. The resource was seen as an information adjunct to specific mechanisms making up a toolkit, to elicit consumer feedback.

It was envisaged that this accompanying toolkit would be developed with the service providers at the selected pilot trial sites, as they identified the types of feedback tools they wished to use eg. focus groups, surveys, open-ended feedback forms.

The booklet was presented to a range of individuals and groups for their consideration and input during the development process including:

- Breast Services Performance Indicator and Standards Project Advisory Committee
- DHS Breast Cancer Reference Group
- VCOG Breast Study Committee
- Consumer Advisory Committees of Southern Health and BreastScreen Victoria

Caring for me? was strongly supported by these groups and considered to have exciting potential for both women and health services.

2.5 Issues of validity and reliability

It is acknowledged that the booklet *Caring for me?* is the work of thirteen women and does not represent the views of women across the state. The booklet is not in itself, however, a method of seeking feedback but is intended to guide women who are asked to comment on the service they have received.

Whatever the methods chosen to elicit feedback on a particular service, the data produced will be women's own words. This material can then be analysed using recognised qualitative approaches that have their own characteristic rigour.

In recent years, the debate about methods of collecting consumer feedback has moved on from a focus on the parametric properties of questionnaire surveys. As the literature on complaints reminds us, priority for service change depends as much on the nature of an event as its frequency. A single adverse opinion can at times carry the same weight as the views of numerous patients. While this approach comes from the medico-legal field, it can also relate to other types of feedback gathered. What makes it appealing in the consumer feedback project is its acknowledgement of the validity of what women say about their experiences.³ Including complaints as one of a number of mechanisms by which information about consumer experiences are gauged will be useful to reducing the negative connotations of a primary focus on negative feedback.

It is believed that the validity of the collection of values in the booklet is confirmed by its synergies with other similar lists. The survey of the literature revealed a number of statements of what consumers look for in a health service. Both the [Australian] Consumer Health Forum and the World Health Organisation (in their patient survey) offer examples. Although the list developed by our Consumer Reference Group is remarkably similar to both, it was chosen to use in preference to these existing sources because it is more directly relevant to the experience of a cancer service and directly represents the words of Victorian women who have experience of the breast cancer service system.

3 Trial of *Caring for me?*

3.1 Objectives

The specific objectives of the trial were to:

- determine the usefulness of targeted consumer feedback activities in generating performance information about breast services provided at the trial sites
- to work with and support the specific service sites to develop and utilise the feedback tools.
- identify those factors that influenced the uptake of the trial within a service.

3.2 Principles

The following principles underpinned the development, implementation and evaluation of the consumer feedback trial.

- The project team adopted a collaborative approach to work with key stakeholders at each participating site to ensure that the trial and resources were tailored to each site's particular needs and interests.
- A supportive environment was created which encouraged organisational learning that recognised and built on service strengths.
- The trial focussed on quality improvement by encouraging the consumer feedback mechanisms to be seen as an integral part of its own service level quality improvement program. As with the broader Breast Services Performance Indicator and Standards Project, the emphasis was on an educative, collegiate approach rather than a punitive one with the Project team maintaining a supportive role.
- Maintaining a balance between the burden of collection and analysis of consumer feedback and value of the process in generating useful information about the service that will ultimately inform future service improvements.

3.3 Method

3.3.1 Recruitment of sites

As indicated two sites participating in the Breast Service Performance Indicator and Standards Project (PISP) were invited to participate in the consumer feedback trial. A third site later expressed interest in participating in this trial. The need to source consumer feedback was identified as a core area for improvement in the breast services peer review visit for this site. One site was also keen to trial *Caring for me?* as a framework for interpreter-mediated focus groups with Cantonese and Vietnamese women within their service.

The three participating sites were:

- Bendigo Health Care Group
- Southern Health, Monash Medical Centre Moorabin Campus
- Western Health.

The three sites were recruited sequentially. Consultations with the first site commenced in October 2004 and their active involvement paralleled their participation in the PISP trial.

While the work with this first site informed further project development, the other sites were provided with the opportunity to develop their approach based on their own needs. Service demands both at a site and Project team level resulted in delays in the development and implementation of the trial at these two sites. As a result, the second site's full participation in the consumer feedback trial did not occur until after their active involvement in the PISP project had been completed.

The third site's active participation was delayed until January 2006 due to time constraints at the service level delaying identification of the population to survey and the ethics application process.

3.3.2 Development of the feedback tool(s)

The initial consultations with key stakeholders at each site explored how the *Caring for me?* resource could be used to support the development and implementation of selected consumer feedback tools.

Through this consultation, all three sites opted for the modification of the *Caring for me?* booklet as a survey tool seeking a mix of quantitative and qualitative feedback from women on their experience of care across each of the eight dimensions.

Following each area of care and its associated quotes and statements in the booklet, women were asked to:

- rate how important this area of care was to them on a five point scale
- rate their experience of this area of care on a ten point scale
- provide comments on their experience.

A guide to using the booklet was also included within *Caring for me?*. A generic version of the booklet used in the trial is included as Appendix 1 to this report.

The use of *Caring for me?* as a feedback mechanism was adopted and trialled at all three sites. At each site minor modifications were made to the tool and it was branded with the service's logo.

The development of a toolkit with a series of feedback mechanisms did not evolve as the health services involved were interested in a feasible and practical trial of the tool that would align with how they would intend to use it in future if demonstrated to be effective.

3.3.3 Selecting and recruiting women for consumer feedback

Participants were women who had received part or all of their breast cancer treatment at the hospital within a given period of time. This varied between sites based on throughput and other issues (See Table 1).

Table 1: Selected participants by site

Site	Selected participants	Rationale
Site One	<ul style="list-style-type: none">• Women who had been or were being treated at the service within the past two years.• Women who were members of local support groups.	To recruit sufficient women and also to allow women time after the completion of active treatment to reflect on her whole experience.
Site Two	<ul style="list-style-type: none">• Women who had been treated at the service within the previous eighteen months	To capture women's experiences at the end of treatment.
Site Three	<ul style="list-style-type: none">• Women who had been treated within past 2 ½ years.	To capture women's experiences who had been treated since the introduction of a full-time BCN role.

Eligible women were identified by personnel at each site according to a local protocol. Ethics approval was sought and obtained from The Bendigo Health Care Group, Peter MacCallum Cancer Centre (for radiotherapy patients at Bendigo) and at Western Health. At Southern Health, a waiver of the need for ethics approval was granted on the basis that the site intended the tool be used to generate feedback on an ongoing basis as a quality assurance activity.

At site one, women were approached personally and asked if they would complete the feedback tool. This was to be done either personally by the breast care nurse, day oncology or radiotherapy staff. Multiple copies of the feedback tool were also sent to local support group coordinators who were asked to give them to interested members who may fit the eligibility criteria for the pilot.

At the other sites a letter was signed by the Unit head and breast care nurse and was mailed to each woman fitting the selection criteria for the site trial along with a plain language statement (sample included in Appendix 2) and one copy of the *Caring for me?* feedback tool. Women were provided with contact details of the Project Coordinator and/or breast care nurse if they had any queries or concerns and a stamped addressed envelope to return the survey once complete.

3.3.4 Data collection and analysis

Women returned the completed questionnaire directly to the Project Coordinator or via a local site contact (for one pilot). The Project Coordinator collated and analysed the data and provided a report back to the service site. In all cases, this process was independent of the service and no service personnel have been privy to the completed surveys. This independence was considered to be an important part of facilitating frank and open feedback.

3.3.5 Maintaining women's confidentiality

The woman's confidentiality was assured with the Project Coordinator having no access to any identifying information about the woman without their consent. All feedback provided back to the site was done so in an aggregate de-identified form.

3.3.6 Project support

As indicated the Project was undertaken as a collaborative venture within each service.

Central Project support was provided at all stages in the Project development and implementation. This support included:

- attendance at meetings with key staff and the Consumer Advisory Committee at one site to inform them of the project and seek their input into the direction of the trial
- tailoring of the consumer feedback tool to the service needs
- development of the plain language statement and letter of invitation for participants
- drafting of all materials including full documentation for two Ethics Committees submissions and assistance with the third
- production of the packages to be sent to women
- collation and analysis of the data
- provision of a report to sites and to women who requested it
- ongoing advice and mentoring.

Site staff:

- facilitated discussion with the consumer advisory committee within one service
- provided input into the development of the site version of the booklet, plain language statement and letters of invitation
- supported the ethics committee submission process
- identified women in the cohort to be approached to participate in the trial
- coordinated the mail-out to women
- facilitated stakeholder discussion on the report received within the service.

3.3.7 Project evaluation

Data for the evaluation has been drawn from a range of sources.

- Response rates for the return of completed survey tools for each site.

- An analysis of women's responses in terms of reflecting how well they understood the tool and could discriminate between the intended meaning of the different values and associated statements.
- Telephone interviews with key contacts at each site to gain their input on those factors that influenced the Project within their service and its usefulness as a quality improvement tool.
- A final meeting of the Consumer Reference Group to review the findings from the trial and provide guidance as to the appropriate next steps for this work.

4 Results

4.1 Site participation

Three sites have participated in the trial of the *Caring for me?* feedback tool. From all three sites, the motivation was a clear desire to gain informative feedback on their service, from the perspectives of the women they treat. This was intended to help identify strengths and opportunities for service improvement.

Other perceived benefits in participating in the trial were that:

- It was a tool that was developed by women with breast cancer for women with breast cancer and provided specific feedback about the breast service.
- It potentially provided feedback on all aspects of the local service and not just one aspect eg breast care nurse practice.
- For one site, participation enabled the site to actively respond to feedback from their earlier peer review visit report and their participation in this trial was actively endorsed by senior management.
- As a 'ready made' tool, it negated the need for staff to undertake the 'daunting' task of developing a valid survey tool for themselves.
- Central support was available to assist in the implementation of the process and in data collation and analysis. This also kept the process independent.
- The use of the tool would demonstrate the breast service as well as the wider hospital's interest in gaining consumer feedback – *'It is an initiative that the hospital and breast service could be proud of.'*

While enthusiasm was high at the site level the barriers to timely participation were organisational. The breast care nurses played a major role in the trial's implementation and this additional work needed to be undertaken within their current workload. While significant central support was given, sites had to support the process through:

- Navigating the service's ethics committee procedures
- Identifying the target women, which in one site required a significant manual search
- Coordinating or undertaking the recruitment of participants.

In one site where women were invited to participate through staff talking directly with them and encouraging them to complete the survey, there was limited evidence that staff other than the breast care nurse had been able to do this in practice. Factors influencing this limited support included:

- Competing workloads
- Staff had to specifically identify and ask breast cancer consumers to participate within a larger pool of cancer patients having radiotherapy or chemotherapy.

Finally because of local time constraints, the use of the tool in interpreter-mediated focus groups with Cantonese and Vietnamese women at one site has not yet been trialled.

4.2 Response rates

A total of 160 women were given or sent the tool across all three sites. Two surveys were returned as undeliverable. A total of 63 completed surveys were returned to the Project Coordinator.

Table 2: Participant response rate by site

Site	Number of surveys sent	Returned to sender	Completed surveys	Response rate
Site 1	65	n.a.	27	42%
Site 2	50	0	10 ¹	20%
Site 3	45	2	28 ²	65%
Total	160	2	63	40%

Of the 63 women who completed the survey 30 (48%) wished to receive a copy of the summary of results once they were completed. The response rate for Site 2 was much lower than for the other two sites. It is unclear why this occurred. A brief questionnaire was developed and distributed to the women from Site 2 to explore the reasons for non-completion. The results of this additional exercise are outlined in section 4.2.1.

Possible factors influencing the general return rate of the consumer feedback survey may include:

- the final length and complexity of the tool and the difficulty understanding the instructions
- the tool would have taken time to complete as it required some reflection and was not a quick 'tick the box' type survey
- for some women, the time period since the completion of treatment may have made the survey appear less relevant or it may have been an experience that they did not wish to revisit
- at site 1, day oncology and radiotherapy staff did not distribute the consumer feedback tool as agreed. This may have been because of; competing work demands; a perception that the feedback would be of less relevance to their service; not being actively involved in the Project at a service level. The personal approach of the breast care nurse appeared to be crucial to encourage participation amongst those who did
- how well the individual woman knew the signatories of the letter; women who knew the signatories more personally may have responded better to the letter.

A report has been developed and forwarded to the three sites for the purposes of reflection and identification of areas for improvement.

4.2.1 Follow-up survey for site two

The follow-up survey for site two was devised to explore the poor response rate to the *Caring for me?* survey in that site. All 50 women in the original sample were sent a brief survey and 34 (68%) responded.

Although only eight booklets had been received by the Project Coordinator, 15 women reported having returned the booklet. With the follow-up survey a further two booklets were also returned (10 in total) bringing the total response rate to 20% overall.

Of the 19 women who reported that they did not complete the booklet, the reasons for non-completion is provided below (Note that a woman may have ticked multiple responses so the total is greater than 19).

¹ Eight surveys were received initially with a further two received subsequent to the follow-up survey

² Includes one verbal response provided by phone

Reason for non-completion	Number	%
It was too complex	5	17.9
It was too long	4	14.3
It was too difficult to understand	4	14.3
I didn't have the time	4	14.3
I didn't want to think about that time of my life	4	14.3
Don't recall receiving the survey	4	14.3
Busy / away and put it aside	3	10.7
Total	28	100

- Almost half of the respondents considered that the survey was too complex, long or difficult to understand.
- For four women, the survey tool was not welcomed as they did not want to revisit a difficult time in their life.
- Four women did not recall receiving the survey and a further 7 women didn't have the time or put it aside when it was received and did not return to it later.

A selection of quotes from the survey are included below:

"I found some of the questions not related to me and simple questions would have been easier to answer."

"A simple multiple choice questionnaire would have been preferable (plus further comments if desired). I am employed full time and found the survey format confronting and time consuming. I cannot speak too highly of my treatment/care in all areas during my illness."

"I went overseas and it was forgotten about! I am sorry."

"I would love to have helped but its something I try not to make a big part of my life right now."

Simplification of the tool to make it less cumbersome and daunting for women to complete will be a key factor in improving response rates in the future and thus the utility of the survey overall.

4.3 Quantitative results – importance and experience

A summary of the quantitative and qualitative results from the 65 completed surveys are outlined in this section.

All the dimensions or areas of care were rated as important aspects of good quality care for women. The following table illustrates the mean rating for each area of care from the highest rating to lowest.

Table 3: Average ratings – IMPORTANCE of each area of care

Area of Care	Average rating - Importance of this area of care	
	Average rating	Range
Best Treatment	4.9	4 - 5
Good Communication	4.9	4 - 5
Respect and Dignity	4.8	2 - 5
Feeling Safe and Comfortable	4.8	2 - 5
Being Supported to Make Choices	4.8	3 - 5
Complete care	4.8	2 - 5
Personalised Care	4.7	3 - 5
Fairness	4.6	1 - 5

- All areas of care were rated highly by women who completed the survey.
- Best treatment and good communication were the highest rating areas of care and were also rated consistently highly by all women (no woman rated these areas as less than 4 out of 5).
- Fairness was not considered to be an issue for a number as reflected in the lower rating and broader range of responses.

Women rated their experience of care on a 10 point scale. The following table illustrates the mean rating of the women’s experience of each area of care from the highest rating to lowest.

Table 4: Average ratings – PERSONAL EXPERIENCE of each area of care

Area of Care	Average rating - Experience of this area of care	Range
Best Treatment	9.2	5 - 10
Good Communication	9.1	1 - 10
Being Supported to Make Choices	9.0	1 - 10
Personalised Care	9.0	1 - 10
Respect and Dignity	8.9	1 - 10
Complete care	8.9	5 - 10
Fairness	8.9	1 - 10
Feeling Safe and Comfortable	8.4	1 - 10

- The feedback to each site was very positive on every dimension of care
- Women provided very positive comments on their care and these tended to focus on:
 - The quality of care provided by individual providers
 - The responsiveness of providers to women’s questions and concerns.
- In each area of care, women rating their experience as a 6 or below provided important information about service gaps or how services could be improved.
- Feeling Safe and Comfortable was the lowest rated area of care in terms of women’s experience. This area of care was rated as highly important to women (see Table 3) and reflects an important area for focus. It signifies the value of the seemingly simple aspects of demonstrating caring through words, gestures and actions.

Whilst the quantitative component of the data that was collected was considered to be valuable from the services’ perspective, it acted merely as a flag for the identification of specific issues from the consumer perspective. Low ratings on the experience of care were analysed in detail to provide feedback on negative experiences and to inform areas for improvement.

4.4 Qualitative results – women’s words

The qualitative data generated from the surveys is described below with examples of the feedback received. These are presented as general feedback and according to the eight key areas of care and represent combined results from the three participating sites.

4.4.1 General feedback

Many women used the general feedback section of the survey as an opportunity to thank the service for the care that they received.

“We were all cancer patients in a wonderful system of care and my ongoing treatment and exercise at all the clinics is giving me a chance to regain my self worth, my stamina and I am getting back to my real self once again. I thank each and every department and every single person for helping me through a very difficult time. You all gave me love and respect and I will remember that always.”

“I cannot fault the support and attention I received and am still receiving. In fact it has been quite overwhelming – always warm, friendly – a very specially chosen team. Always explaining every move, the next step and the support systems in place. I never feel alone.”

"Every time that someone approached me to see how I was doing or feeling I felt like someone very close to me was there, talking to me, encouraging me, every step of the way."

"I was terrified and therefore I could easily become irrational, but I never once felt that the staff didn't understand the immensity of the situation I was in. They were kind and caring and I know they really "got" the place I was in."

For some women, areas for improvement were suggested in their general feedback including:

- the need to be more flexible for women with particular needs eg. Working women with young families
- offering alternative means of relieving anxiety and stress during treatment such as yoga or meditation
- one woman who experienced a collapsed vein and significant lymphoedema subsequent to chemotherapy treatment
- busy clinics with doctors who are rushed.

4.4.2 Being supported to make choices

A mix of perspectives were expressed in this area of care from women who were very comfortable to leave the decision making to their doctors to those who wanted to be an active partner in decision making processes.

"All the doctors who treated me are specialist in their own field so, I did not think twice on their recommended treatment. I did not insist on my own choice with treatment because they have explained to me the advantage of their recommended treatment."

"I placed all my trust in the advice given by my surgeon and breast care nurse. The service given by them greatly helped my family and myself through this dreadful ordeal."

"I was given much information on my particular type of breast cancer, supported when my choice may have differed from professionals and most of all, plenty of time devoted to me. I did not feel rushed or hassled because the waiting room was full."

"I believe my surgeon/oncologist allowed me to listen to their advice but ultimately respected my choices."

Two areas for improvement emerged from this area of care relating to a number of women who felt they were not provided with choices regarding treatment and in some instances also felt their decisions and treatment were rushed.

"I wasn't given a choice, just told I would need radiation treatment for 6 weeks."

"After diagnosis, I was asked to be ready for surgery in the morning"

"I would have liked some information and advice before being bluntly asked "Do you want a mastectomy or a lumpectomy?"

4.4.3 Best treatment

The area of best treatment was interpreted in two ways by women who responded to the survey. The first related to perspectives on the team of clinicians who cared for the women, how they facilitated understanding about the treatment and its side effects.

"The doctors and nurses advised me thoroughly on the treatment available. I felt comfortable asking of the side effects and felt confident I was advised and offered the best treatment for a speedy and full recovery."

"Best treatment was very important to me; I was recommended chemo and hormone therapy. I was assured that I was receiving the best treatment. That assurance was vital to me."

"I was glad to have the back up of a breast care nurse, my heart specialist as well as my GP to help."

"Before surgery and all through treatments staff always introduced themselves and explained what they would be doing very clearly. Plus any side effects, so you would know if anything was wrong."

The second interpretation was of best treatment as demonstrated by how well the women felt cared for reflecting issues of communication, sensitivity and supportive care.

"I received excellent care in hospital, the breast cancer nurses were a wealth of information. My radiation oncologist was sensitive to my fears and my medical oncologist is a darling, she has been really supportive."

"Whenever I went to hospital I found every member of staff excellent. I was never frightened once I got to know the staff they were just so kind and tolerant they went out of their way to be so kind and make me very comfortable."

Areas for improvement emerging from this area of care include:

- breast care nurse support being limited only to the surgical component of the pathway
- confusion about the nature of tests and why they were needed
- clinic waiting times
- seeing different doctors each time that the women attended for a check-up
- difficulties in the delivery of a team-approach to care over busy periods of the year.

"The breast care nurse only 'supported' me through the surgery - once chemo started and then radiotherapy I have not had any contact - other than to do this questionnaire. Admittedly I have not contacted her either as I had unspecific needs. I just needed 'support' which seemed to disappear."

"On attending for check up at the breast clinic I found it upsetting to be seen by other doctors other than the surgeon that did the operation and waited in the clinic far too long."

"Whilst I knew I had a team of people caring for me, this process faltered due to the time of year I was treated - Christmas/NewYear - Part of the team were on holidays and I had to wait for a final opinion between operations - quite stressful and isolating."

4.4.4 Complete care

Women responded to the area of complete care in relation to feeling cared for as a whole and of feeling supported. Some women commented on complete care in relation to alternative therapies. Some key positive experiences conveyed were:

- the value of and support provided by the breast care nurse
- ward and physiotherapy after care and education
- the value of meeting other women who have had breast cancer.

"I was listened to and allowed to feel whatever I felt without judgement - which I was grateful for."

"I was pleased that my doctor was open to discussion about complementary therapies."

"The breast care nurses were tuned into my feelings and emotions and were extremely helpful."

"Help was always available with every aspect of my care and I took up the support offered."

Areas for improvement emerging from this area of care include:

- the importance of a simple 'how are you feeling?' and how it can sometimes not be asked
- a greater openness to discussions of alternative therapies such as ways of dealing with anxiety and the emotional toll of treatment

"I can't really recall the staff even asking me how I was emotionally after surgery while I was in hospital, only asking if I was okay physically. My oncologist asked me this question though."

"Complete care is offered - I have not sought out alternative care but I don't feel it would be supported."

"I would like to have seen the surgeon during my stay, but perhaps he was busily engaged with more pressing duties."

4.4.5 Fairness

Responses to the area of fairness raised a range of issues about access (being treated close to home when possible), a response to language, beliefs or financial issues. For a number of women who felt well supported or did not have financial concerns, they considered fairness did not apply to them.

"My treatment was close to home and my times for treatment were made suitable so I could still work."

"Financial help is or was my main concern and I have had help from not only Centrelink, MediCare but others as well."

"I don't believe I had any great need for fairness, but felt comfortable enough that should I have needed it, it would have been available."

"Because English is my second language, I knew I would require assistance. An interpreter was always offered to me, so that I could receive the same type of options as any other patient, without the language barrier becoming a problem."

Areas for improvement emerging from this area of care include:

- inflexibility in appointment scheduling and limited notice of appointments
- raising awareness of the supports that are available.

"I was treated well except for scheduling radiotherapy appointments and lymphoedema clinic. Actually appointment scheduling is poor all round."

"I don't think that you get told about all the support that you can get if you need it."

4.4.6 Feeling safe and comfortable

Feeling safe and comfortable was reflected in perspectives about the friendliness of staff, having a good rapport or the small human touches that can make a significant impact on an individual's sense of being well cared for.

"The nurses at hospital were fantastic - very supportive; one particular nurse who had been through breast cancer herself, told me about her diagnosis, this helped me a lot to see someone recover and come through breast cancer."

"I'll never forget the kindness of an orderly just before surgery who gave me a warm blanket for my very cold feet."

"I always felt very comfortable with my surgeon because of his cheerful disposition. More so with my breast care nurse who is so aware of my physical needs but particularly my emotional. My journey was made so much easier with the availability of a BCN. She is an integral part of the process."

A range of comments reflect areas for improvement emerging from this area of care principally reflecting negative experiences in relation to friendliness and caring approaches by staff.

"To be placed in a ward with men before the operation was unbearable for me. But the breast care nurse stepped in and I was then placed in a ward with another lady. One nurse told me I would just have to cancel surgery if I did not like it."

"I think this is very very important not only for myself but for all the patients in the hospital. I say this because some of the staff are not that friendly with no smile on their face."

"Some of the doctors other than those in charge could be better at communicating but that may be experience."

"The only negative experience I had was the nursing staff on my second night in hospital. I know I was emotionally vulnerable but I felt like a leper...It only takes a smile and a friendly word."

4.4.7 Good communication

Good communication was reflected through approaches that supported the woman to ask questions, where information was provided in multiple forms and was simplified where possible.

"When I asked the meaning [of any medical jargon I didn't understand], no one made me feel stupid and explained everything in layman's terms and even drew things for me."

"I found communication easy because of the personalities of my carers. I was always comfortable in asking questions and asking again if I didn't understand. I was never trivialised."

"Because I had the language barrier, I always had an interpreter or family member with me, but I was always asked personally if I understood all the steps and procedures. I never felt uninformed."

"All forms of the communication were excellent, videos, booklets and staff. Books were particularly good as at home a question may surface and you have a reference to turn to."

Areas for improvement emerging from this area of care include having the time and space to ask questions and whether women felt fully informed.

"I felt a little like I was not given the 'whole' picture but bits and pieces as I went on. Eg I was not even aware that I could avoid radiation therapy if I opted for a mastectomy (which I ended up needing) as I was being advised to have a lumpectomy."

"My only criticism is that sometimes in the breast clinics and breast oncology clinics doctors are different and do not always have the time to discuss issues. They appear rushed."

4.4.8 Personalised care

Personalised care was interpreted by women as receiving care that took into consideration their personal circumstances, medical history, their beliefs and preferences and life beyond breast cancer. A sense of the woman being valued was conveyed when these things were in place.

"I was treated as a whole person. Those who cared for me asked me about my life and spiritual issues that were important to me."

"I was asked about my living situations, offered many services available making sure all my concerns were covered before surgery, giving me a clear mind for recovery."

"I am a diabetic on insulin so personal care is very important. I was given every assistance with medication and diet."

"Being aware why I was actually there for each appointment and knowing what had been discussed or decided upon at previous appointments is important; this makes me feel important, not just a number."

Once more, the importance of simple kindnesses were noted:

"You really remember the staff who take that time."

Areas for improvement emerging from this area of care reflect instances in which interest in or attention to the woman's needs and preferences was not conveyed.

"Doctors did not always show interest in my personal situation. But I felt happy that they were doing to do the best for me and were more absorbed in my medical situation."

"I was given no choice of [radiotherapy] appointments and no lifestyle (having 4 school age children) was taken into account when scheduling appointments. I very much felt like a patient rather than a person in this department."

"The anaesthetist did not accept my anxiety about my previous experience under anaesthetic even though I warned him that I was asked to pass on the message that I was extremely sensitive to narcotics. That unnerved me a little."

4.4.9 Respect and dignity

Respect and dignity was shown in the treatment that women received through attention to issues of privacy, through being listened to and allowing discussion of issues and fears and through minimising waiting times where possible.

"My experience with both the surgery and treatment was all positive. Never once did I feel like a number or "just another patient". I was treated as a 'person, mother' and as a 'women', for this I am grateful. Even when told of the chances of the cancer re-occurring I always felt I would be treated with respect, and will once again the hopeful outcome of a full recovery."

"Respect and dignity are very important as this type of treatment changes who you feel you were physically and mentally."

"In such a busy clinic I am always amazed at how doctors can find the time to treat me with such interest - on a personal level as well."

Areas for improvement emerging from this area of care reflect issues of privacy:

"My one major room for improvement was when some doctors were doing rounds, curtains were not used and when doctors were talking between each other, patients were privy to my medical history. My privacy was and still continues to be very important to me and its my choice whom I share this with."

"The only problem was at the radiotherapy room each time new groups of people and especially too many men around (I mean for being exposed and embarrassed)."

"Sometimes examination doors were opened while I was lying half dressed on examination table, sometimes this was distressing."

"I feel they need people that have gone through breast cancer so they can put people at ease with any fears or concerns they may have that everything will turn out alright."

4.5 How have the results been used?

At Site 1 the results of the trial were presented to the Breast Services Executive Team and to the broader multidisciplinary team. Broader circulation and presentation of results is planned within the radiotherapy, oncology and surgical team. Within this service, there was very strong interest in the findings by service providers and the report provided them with useful feedback in some unexpected areas eg

- The need for improved scheduling of radiotherapy appointments to better accommodate women's other responsibilities.
- The need to better coordinate follow-up appointments.

While service gaps or issues were only identified by a small number of women within each dimension at this site, the strength of the feedback made a significant impact. A final report with all responses analysed has been provided to the site and will be considered by a newly formed consumer advisory committee that reports to the Board of Management of the hospital. A steering group has also been formed to evaluate service provision and make improvements.

At Site 3, the review of the consumer feedback has been an important task for a newly formed breast cancer consumer reference group. It was also considered as a part of an annual breast service strategic planning session.

At Site 2, the follow-up survey for non-respondents has provided some useful directions for how the tool can be better used within their site or refined in general. A report has recently been provided to the service based on the limited number of surveys that were received. There is a commitment to further pursuing this work to establish a method for gauging consumer feedback on an ongoing basis and a focus group is currently planned.

4.6 Results summary

The survey results reflected the strengths of each service and also identified areas where improvement activities may be precipitated. The use of the *Caring for me?* resource as a key component of the survey has prompted women to provide a rich description of their experience and their feelings. The quantitative data demonstrated the importance of the areas of care to women in general and that the rating of experience was generally very positive.

There are potential limitations with any survey that has a limited response rate and relies largely on qualitative responses. Questions about whether these results could be generalised may arise. However, the focus of this work has been on generating information that would be of use to a service in reflecting upon the quality of care provided. In several instances, the comments made by women reflected issues that are known to the service and added weight to the case for change. At Site 1, whilst a number of areas within the hospital expressed interest in distributing the survey, the breast care nurse became the primary person who spoke with women and provided the survey. It was not a key point of focus for the other personnel and it fell away in their busy practices. A decision was also made by the breast care nurse about who they would provide the survey to, depending on where the woman was at in her treatment journey at the time. This may have introduced bias into the sample for that site.

A further limitation of the results is the generally high ratings, particularly for the rating of the importance of each area of care. This may reflect a potential bias with those with a more positive experience potentially being more likely to respond to such a survey. Over time, with additional numbers, useful information may be generated about trends in relation to experience or perceptions of value of the specific areas of care.

The use of two varying scales was raised by the Consumer Reference Group as a point of potential confusion and a consistent scale would address this.

In some instances, there was a different interpretation of each area of care by the women. Whilst initially considering this a potential issue, it could be argued that the value of *Caring for me?* is that it provides scope for a woman to interpret the areas of care in her own way and respond according to her individual values and experience. Building appropriate techniques for the analysis of the qualitative data that is generated over time can address this through thematic analysis of themes and issues emerging across all areas of care.

The strength of the *Caring for me?* approach is that the results are well grounded in real experiences of the women who have been treated within a service. The results are tangible and relevant to the service.

5 Learnings

Toolkit

Caring for me? was originally intended as a resource for consumers informing them about what they may expect within a quality service. It was designed to encourage women to provide feedback to the service using a range of other resources to be developed as part of an accompanying toolkit.

The development of this subsequent toolkit did not eventuate due to:

- Preferences of health services. Services when approached, stated they would prefer a survey tool to be developed rather than a range of consumer feedback mechanisms. They stated that this would enable the tool to be adapted and used to inform and direct further quality improvement processes within their service.
- Availability of time. The time required by health services in implementing a number of feedback mechanisms was seen as problematic.

The toolkit was subsequently redesigned as an information resource and a data collection tool (Appendix 1). The tool was then trialled as outlined in the methodology section of this report.

Methodology

When reviewing the responses to this small-scale trial, the following points were noted regarding the method and timing of distribution, and collection of the surveys.

- The availability of central support was important in facilitating and supporting the sites to implement the study, including evaluation expertise to analyse data and present it back to the sites in an easily comprehensible way.
- Difficulties and delays arose with the limited resources at the site level and the inability in at least one site to be able to easily identify women from health information records.
- The samples selected and mechanisms for distribution were not standardised in this trial. The different rationales for selection and process for selection are detailed in Section 3 of this report.
- Participation of the health service in other projects may have influenced their capacity to participate in this project. Eg. *The Breast Performance Indicators and Standards Project*.

Of the surveys returned, there was an overall positive response to the survey questions. For the survey to potentially provide a broader range of feedback, the method of distribution and timing of the survey require further examination. Although the sensitive nature of the clientele in this project is not underestimated, may also need to be a way of distributing the surveys to increase validity.

Other ways of using the tool

In this trial the *Caring for me?* document has been used as a survey tool. This tool could be used to encourage feedback that might be elicited through a range of mechanisms such as:

- open-ended feedback forms
- complaints
- suggestion box
- patient advocate
- surveys
- focus groups
- individual interviews.

For this purpose a modified tool has been developed to be used as a stand alone resource that could be provided to women at any point during their care to allow them to reflect upon other women's experience and to encourage them to provide feedback (Supporting

Documentation-in booklet format). A modified separate survey tool is also included in Appendix 3.

6 Summary

The *Caring for me?* resource provides an alternative to purely quantitative satisfaction surveys and allows the generation of qualitative information that was considered of value to services to inform areas for improvement. It can act as a useful adjunct to quality improvement activities within hospitals and is considered of value to consumer advisory committees who are interested in understanding the experience of care of their patients.

It is recognised that a range of mechanisms are required to provide accessible consumer feedback. The needs of specific population sub-groups and needs in relation to language, culture, literacy levels and disability would need to be considered in the tailoring of resources. This would allow individual preference for feedback to be considered and would potentially increase the response rates of the consumers as personal preference is taken into account.

References

1. BreastCare Implementation Advisory Committee. 1999. Breast Disease Service Redevelopment Strategy 1999 – 2003. Melbourne: Victorian Government Department of Human Services.
2. The development of performance indicators for hospital breast services in Victoria. 2004. Melbourne: Victorian Government Department of Human Services.
3. Mulcahy, L (2003) *Disputing doctors: the socio-legal dynamics of complaints about medical care*. Buckingham, Open University Press.

Caring for me?

*Providing feedback
about my care*

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Introduction

Having tests to see if you have breast cancer, or having treatment for breast cancer, can be a stressful time.

It is important that your time in hospital is as good as possible with treatment of a high quality. But when you have had little experience of illness and hospitals, you may be unsure about what is 'good quality care'.

To help you think about the care that you have received, this booklet has been developed by a group of women, most of whom have had breast cancer. They started by naming the key things that they felt would be part of good quality care. Then they listed the different ways these might be shown by those providing the care.

We know that every woman's experience will be different as will the issues that are important to you. Some of the statements in this booklet may ring true to you, others will not.

The following page shows how the booklet is set out and gives an example of how one area has been described.

Providing feedback to the hospital is very important. Feedback from women helps the breast service to reflect on the care they provide. Added to other kinds of information, it can suggest areas for change and improvement in the service. Taking some time to provide your personal thoughts on the care you have received, regardless of where you are in your treatment journey, can help to improve the care that you will later receive or that other people in a similar situation will receive.

To help us consider the feedback you provide, please indicate the types of treatment you have received by ticking the boxes below.³

My treatment included:

- | | |
|-------------------|--------------------------|
| Surgery | <input type="checkbox"/> |
| Chemotherapy | <input type="checkbox"/> |
| Radiation Therapy | <input type="checkbox"/> |
| Hormonal tablets | <input type="checkbox"/> |

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³ This question was included for two of the three trial sites

A Guide to this booklet

To help you in reading this booklet, the different parts are explained here.

- Being supported to make choices
- Best Treatment
- Complete Care
- Fairness
- Feeling safe and comfortable
- Good communication
- Personalised care
- Respect and dignity

Areas considered important to good quality care.

Women talking about respect and dignity...

'The fears I expressed were taken seriously and reduced by the way I was treated.'

'I felt I was treated as a person rather than just another patient – 'the left or right mastectomy''.

The boxes on each page contain quotes from women who have attended a breast service relating to that area of care.

How could respect and dignity have been shown during my care?

The doctors listened to me and encouraged me to ask questions

My personal information and need for privacy was respected.

These are some ways that may indicate you've been treated with respect and dignity. Different statements and areas of care will have different meanings or importance to each person.

How important to you is respect and dignity?

Not important at all

Extremely important

Your perception of how important this area of care is to you. You may indicate your view from 'Not important at all' to 'Extremely important'

Your experience:

A place for you to record your experience in this area.

Rate your experience in this area:

Give a rating out of 10 (1 = very poor, 10 = very good)

Your rating of your experience in this area

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Being supported to make choices

Women talking about being supported to make choices...

'This was too big for me to decide without help. I told the surgeon I needed her to make a recommendation.'

'My decision was different from the doctor's recommendation, but he respected and supported my choice.'

How could I have been supported to make choices?

I was asked at the start and along the way how much say I would like in deciding about my treatment.

When I asked for information to help me in making treatment choices, I was given what I needed.

All along, I was encouraged to read and ask questions to help me make an informed choice about what treatments to have.

I was given time to take in and deal with the cancer news and the impact on my family. This meant I could organise help for my family before I had to make decisions about my care.

How important to you is being supported to make choices?

Not important
at all

Extremely
important

Your experience:

Rate your experience in this area:

Give a rating out of 10 (1 = very poor, 10 = very good):

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Best treatment

Women talking about best treatment...

'I wanted to feel secure and confident that the doctors and other staff were a group of experts who would provide me with the best chance of a full recovery'.

'At the end of the day, getting the best treatment I could have was most important to me.'

How might I know I have received best treatment?

Before surgery, I was told about the team of people looking after me and what each person would be doing for me.

I was introduced to the person who would be my main contact during treatment.

When I asked, I was informed of the training and experience of the staff who treated me.

I was able to talk to and contact the breast care nurse when I needed.

I was provided with the verbal and written information that I needed about breast cancer treatment.

I received excellent treatment and care even though I was at a small rural hospital.

How important to you is best treatment?

Not important
at all

Extremely
important

Your experience:

Rate your experience in this area:

Give a rating out of 10 (1 = very poor, 10 = very good):

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Complete care

Women talking about complete care...

'I like the way my feelings and needs were considered.'

'I was pleased that my doctor was open to discussions about complementary therapies.'

'My doctor supported my use of yoga as a relaxation method.'

How might I know I have received complete care?

The staff often asked how I was feeling, emotionally as well as physically.

When the staff couldn't help me with a particular concern, they offered to arrange help from someone else.

I was encouraged to talk about everything that concerned me, not just the breast cancer.

How important to you is complete care?

Not important
at all

Extremely
important

Your experience:

Rate your experience in this area:

Give a rating out of 10 (1 = very poor, 10 = very good):

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Fairness

Women talking about fairness...

'I just wanted to be given a fair go.'

'Although I chose to be treated in Melbourne, my doctor arranged for me to have some of my treatments locally so I didn't have to travel every week.'

How could fairness have been shown during my care?

When I had a particular need, the hospital was able to assist.

I was told about the different kinds of practical support I might need and was shown how to ask for these services if I needed:

- Financial support
- Travel and accommodation
- Child care

Interpreters were available to help me understand my diagnosis and treatment.

My religious and cultural beliefs were respected by those who cared for me.

My doctor was open to exploring ways for me to be treated near home so I wouldn't have to make so many long journeys.

How important to you is fairness?

Not important
at all

Extremely
important

Your experience:

Rate your experience in this area:

Give a rating out of 10 (1 = very poor, 10 = very good):

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Feeling safe and comfortable

Women talking about feeling safe and comfortable...

'Because I knew what to expect after surgery, I felt reassured and confident that I could handle it. It's the unknowns that are scary!'

'Nursing staff could tell when I needed a shoulder to cry on, which was often.'

'One nurse was great at fixing my pillows in the middle of the night to make me comfortable.'

'A nurse gave me a really silly ugly monkey that made me laugh every time I looked at it.'

How could I have been made to feel safe and comfortable during my care?

A nurse went with me to surgery – this made me feel better.

Because both my emotional needs and my physical needs were looked after, I felt that I was receiving good quality care.

It helped a lot when the nurses talked to me about how I was doing.

I felt that the staff cared about the people who are important to me - my family and friends.

The staff checked my medical history whenever it was necessary.

The staff treated me honestly and kindly and told me clearly what was happening.

How important to you is feeling safe and comfortable?

Not important
at all

Extremely
important

Your experience:

Rate your experience in this area:

Give a rating out of 10 (1 = very poor, 10 = very good):

Good communication

Women talking about good communication...

'Over time I felt myself asking more questions as I became more informed and confident – I formed a stronger bond with the doctors.'

'Having a personal record of my diagnosis and treatment helped me to understand the different aspects of my treatment.'

How could good communication have been shown during my care?

The staff made an effort to explain medical terms and procedures and checked that I understood.

I had a choice of information in different forms – paper, cassette tape, video, internet sites.

The staff encouraged me to feel hopeful.

I was given enough time to consider my options and make decisions that I felt comfortable with.

The staff encouraged and supported the involvement of the people close to me.

When I asked for information about my specific treatment, this was given to me.

After telling me my diagnosis and treatment choices, the doctor said it was OK for me to phone after a day or two if I needed to check something.

How important to you is good communication?

Not important
at all

Extremely
important

Your experience:

Rate your experience in this area:

Give a rating out of 10 (1 = very poor, 10 = very good):

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Personalised care

Women talking about personalised care...

'My oncologist remembers my stories about my family and asks about them when I return to see him.'

'I told the anaesthetist about my previous bad experiences with painkillers and sedatives, and she reassured me about the ones to be used.'

'As a young woman, the effect of treatment on my fertility was my greatest concern. I needed this to be factored into any decisions.'

How could my care have been personalised?

I was treated as a whole person. Those who cared for me asked me about my life and my needs such as my living situation, my particular concerns and any cultural and spiritual issues that were important to me.

My treatment plan was worked out in a way that catered for my concerns and personal circumstances.

Before offering medications, the staff checked my medical history with me.

How important to you is personalised care?

Not important
at all

Extremely
important

Your experience:

Rate your experience in this area:

Give a rating out of 10 (1 = very poor, 10 = very good):

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Respect and dignity

Women talking about respect and dignity...

'The fears I expressed were taken seriously and reduced by the way I was treated.'

'I felt I was treated as a person rather than just another patient – 'the left or right mastectomy''.

How could respect and dignity have been shown during my care?

The doctors listened to me and encouraged me to ask questions

My personal information and need for privacy was respected.

I was suitably clothed and the focus was on me (with no distractions) when important things were being discussed.

I was given an explanation and apology when kept waiting.

How important to you is respect and dignity?

Not important
at all

Extremely
important

Your experience:

Rate your experience in this area:

Give a rating out of 10 (1 = very poor, 10 = very good):

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Appendix 2 - Example of Plain Language Statement

Caring for you
Seeking feedback from women affected by breast cancer
to improve the quality of care.

We would like your input in a project with women with breast cancer about their experience of care within *Site One*. A booklet has been developed by a group of 13 women from across Victoria, 11 of whom have had breast cancer. The booklet called ***Caring for me?*** provides the thoughts of these women as a prompt for you to reflect on the care you have received. In response, you may consider describing your experience of care to *Site One*. This will help them to understand the quality of the care they provide from the perspectives of the women they treat.

Who is eligible to participate?

Women who have had breast cancer within the past three years and received some or all of their treatment with *Site One*.

How will information about your experiences be used?

Responses for women who return the completed booklet will be summarised and considered by the team of people involved in the delivery of breast services at *Site One*. They will be discussed and potential areas for improvement identified as a part of a quality improvement project over the coming year.

What do you need to do?

Take the booklet and information about this study and read them at your leisure. If you decide to participate in the project, the steps you would need to take are:

- Read the ***Caring for me?*** booklet and reflect upon the care you received from *Site One*
- Complete the 'your experience' section in any or all of the sections in the booklet that you would like
- Complete the questions at the bottom of the following page
- Return the completed booklet in the stamped, self-addressed envelope provided

How will your privacy be respected?

All responses will be treated with the strictest of confidentiality. If you wish, your responses can be provided anonymously. If you provide contact details, these will be stored in a separate location to the booklet and will only be accessible to the Breast Care Nurse consultant. Your contact details will only be used for the purposes to which you have consented at the end of this form. There will be no identifying information used in any reports, publications or other written materials arising from this project. Records will be kept for five years after completion of this study, however they will not include identifying information and will be stored in a locked cabinet, only accessible to the Breast Care Nurse consultant.

What do you do if you have any concerns about the study?

This study has been approved by the Ethics Committees of *Site One*. If you have any queries about the study that are not addressed by this information, feel free to contact Alison Amos who is the principal investigator for this project on (03) 9885 2123 or via email at amos10@bigpond.com. Alternatively, you may wish to contact the Secretary of the Ethics Committee on <phone number>.

- - - - -
- - - - -

Please complete this section of the form, detach and return with the completed study booklet

Please tick the box or boxes that apply to you:

1. I would like my feedback to remain anonymous
2. I would like to receive a summary of the results of this project
3. I would like to receive information on other activities eg. focus groups that will be undertaken as a part of this project

If you have ticked the boxes for question 2 or 3 above, please provide your name and contact details:

Name: _____

Address: _____

Phone: _____

Email: _____

Appendix 3 – Revised *Caring for me?* survey

**Caring for me?
Providing feedback about my care**

Providing feedback to a hospital breast service is very important. It assists the breast service to reflect on the care they provide. The below revised survey tool is advised to be used in parallel with the revised *Caring for me?* Booklet (under supporting documentation–in booklet format), to allow women to provide feedback on the care they received.

Please tick the types of treatment you received:

Surgery

Chemotherapy

Radiation Therapy

Hormonal tablets

Being supported to make choices

How important to you is being supported to make choices?

Not important Extremely Important

Please rate your experience in this area:

Very poor Very good

Please describe your experience of 'being supported to make choices':

Best treatment

How important to you is best treatment?

Not important Extremely Important

Please rate your experience in this area:

Very poor Very good

Please describe your experience of 'best treatment':

Complete care

How important to you is complete care?

Not important				Extremely Important
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please rate your experience in this area:

Very poor				Very good
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please describe your experience of 'complete care':

Fairness

How important to you is fairness?

Not important				Extremely Important
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please rate your experience in this area:

Very poor				Very good
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please describe your experience of 'fairness':

Feeling safe and comfortable

How important to you is feeling safe and comfortable?

Not important				Extremely Important
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please rate your experience in this area:

Very poor				Very good
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please describe your experience of 'feeling safe and comfortable':

Good communication

How important to you is good communication?

Not important	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Extremely Important
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Please rate your experience in this area:

Very poor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Very good
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Please describe your experience of 'good communication':

Personalised care

How important to you is personalised care?

Not important	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Extremely Important
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Please rate your experience in this area:

Very poor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Very good
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Please describe your experience of 'personalised care':

Respect and dignity

How important to you is being treated with respect and dignity?

Not important	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Extremely Important
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Please rate your experience in this area:

Very poor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Very good
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Please describe your experience of being treated with 'respect and dignity':

**Thank you for taking the time to reflect upon your experience and provide us with feedback.
This information is important to inform improvements to services in our community.**