



# Western Breast Services Alliance Consumer Feedback Project

January 2003



## Project Report





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## Acknowledgments

This Consumer Feedback Project for the Western Breast Services Alliance was a Project our team found both challenging and rewarding.

My thanks go to Sheila Hirst from the Western Breast Services Alliance for her continuing support and feedback throughout the course of the Project, especially her recruitment of suitable women for interviews or focus groups.

The women who gave their time to provide us with the data presented in this Report were generous and brave. They managed to describe their sometimes alarming experiences with the aplomb and candour that has made this Report the rich reference material that it is. They often expressed the need they felt to tell all in order to benefit other women.

To these women who willingly participated in providing consumer feedback we express our heartfelt thanks and admiration.

I would like to thank the Jenny Ashby and Associates Project Team :

- Tamara Protassow, who conducted all the telephone interviews and assisted with one of the focus groups, and undertook analysis and report writing;
- Michelle Jones for her patience with expert formatting and word processing;
- Cathryn Phillips for organising the venues and arrangements for the focus groups; and
- Michael Ashby for editing and general support.

We support the hope of the women involved in providing feedback that the data and analysis in this Report benefits the women who may need to seek the services of those involved in the diagnosis and treatment of benign breast disease symptoms.

We entrust this Report to the service providers involved and look forward to seeing the consumer feedback data influence service improvements in the field.

Jenny Ashby  
January 2003



## Executive Summary

### Background

A Consumer Feedback Project was undertaken in 2002 by the Western Breast Services Alliance (WBSA). The WBSA is a group of public and private service providers (hospitals, doctors, and specialists) who are working together to implement the Breast Service Enhancement Program (BSEP).

The purpose of the Consumer Feedback Project was to seek women's views on their experiences of a breast symptom and their interactions with diagnostic and management processes in the health system.

Women consumers' views were to be sought on:

- experience of and satisfaction with services within the diagnostic pathway
- factors that influence women's anxiety, both within the system and personal coping strategies
- their understanding of their condition and how well their information needs were met
- opportunities for future service improvements.

### Methodology

Collection of qualitative data was obtained from women consumers through two focus groups (Sunshine and Footscray) and fourteen individual telephone interviews. In all, 18 women participated in the Consumer Feedback Project. WBSA service providers obtained initial written consent from women attending clinics who indicated interest in participating. The Project Consultants were given 39 women to contact, and over 65 telephone calls were made to give women the choice of providing feedback via focus groups or telephone interviews.

The 18 women who participated were all asked the same pre-set questions. The focus groups were held over two hours and the richness of data obtained from the four women participants enabled case studies to be written of the women's experiences. The telephone interviews took approximately 30 minutes each.

### Demographics

The 18 women consumers who participated ranged in age from 25 to 57 years, and it was the first breast problem for nine of them. Seven of the women had some family history of breast cancer. Nine women cited their ethnicity as Australian / Anglo-Saxon, two were Philipino, two Maltese, one Russian, one Egyptian and one Turkish.

### Key Findings

The key findings from consumers were:

- the initial response to discovering a breast symptom for most women was panic, shock, fear and disbelief

- most women relied on General Practitioners (GPs) for initial information, and to facilitate smooth transition from generalist to specialist treatment
- communication problems at this first contact can cause higher stress levels for women, as GPs appeared to have a great influence on how women approach their breast problem
- most women were only reassured when they saw the Specialist. They relied on this meeting for information and to have their questions answered
- good communication and more time were areas of improvement women sought from Specialists
- that testing procedures were perceived as less uncomfortable and painful if operators were friendly and talked to them, explaining the procedures
- explanation of testing procedures before and during tests reduced women's anxiety
- waiting had a significant impact on women's stress and their ability to cope / function, with some women waiting 4 to 6 weeks to see a Specialist
- most women experienced long periods of time in waiting rooms
- women were only given verbal information. Most women thought written information would be helpful. Some women felt written information would raise unanswered questions and therefore preferred verbal information. Some women searched the Internet but could not find information in plain English
- women relied on networks of family and friends to support them and help them cope. Some women found sharing stories with other women who had been through similar experiences helped them cope
- fear of the unknown was the single biggest anxiety, and women with a family history of breast cancer found that this increased their anxiety levels
- most women's anxiety dropped after seeing their Specialist and / or getting their test results.

The Consumer Feedback Project Consultants suggested, based on the consumer feedback, there needed to be improvements that reduced women consumers' anxiety; improvements in training and service delivery by health professionals; and improvements in information provision to consumers.

## **Recommendations**

Five specific recommendations were made that focus on reducing the length of waiting time for women consumers as they interact with the health system.

Training for health professionals, particularly the need for good communication skills and efficient service to reduce women's anxiety; having an information strategy with multiple approaches and delivery methods; undertaking a process analysis to identify delays and opportunities for streamlining; and developing regular consumer feedback mechanisms to inform further breast service improvements.

## Recommendations

Based on feedback from consumers, it is recommended that the Western Breast Services Alliance, through the Breast Services Enhancement Program, implement the following service improvements.

### Recommendation 1

Reduce the length of time between referral, testing and diagnosis results being communicated to women, as this has a significant impact on the anxiety of women consumers. The WBSA needs to work to establish a goal of what can be considered a reasonable waiting time for all parts of the process that women undergo.

### Recommendation 2

Training of health professionals working with women with breast disease should highlight these women's needs within the health system. Training should cover better communication skills, compassionate treatment and streamlined / quick service to reduce the anxiety of women and enhance health outcomes. Case Studies of women consumers from this Project can be used as a way of taking the consumer voice into the training.

### Recommendation 3

An information strategy with multiple approaches and delivery methods should be introduced to better inform women consumers with benign breast disease about possible impacts and experiences related to their conditions. In particular, coping mechanisms and what strategies can reduce their anxiety as they undergo the experience of testing and diagnosis. Sharing stories of women's experiences can be an effective way of conveying information.

### Recommendation 4

A process analysis should be undertaken to identify where, when and why delays occur for women consumers as they interact with the health system and how processes can be improved to provide better services for consumers, using the consumer feedback as a guide.

### Recommendation 5

Regular feedback mechanisms need to be developed and established to use women consumer's voices to inform further breast service improvements. These feedback processes should be a standard format across all services in the Western Breast Services Alliance.

## Section 1 Project Context

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### 1.1 Introduction

This report discusses the results of consumer consultations undertaken as part of a Breast Service Enhancement Program (BSEP) for women with benign breast disease / breast problems. The Program is being undertaken by the Western Breast Services Alliance (WBSA). The WBSA is a group of public and private service providers who have come together to implement the Breast Service Enhancement Program (BSEP).

Membership of the WBSA BSEP includes Melbourne Health, Western Health, The Women's and Children's Health Service (Royal Women's Hospital), Freemason's Hospital, Melbourne Private Hospital, Frances Perry House and Western Private Hospital and individual service providers (doctors and specialists).

This Project focussed on obtaining consumer views on their experiences of a breast symptom and the diagnostic and management processes women encountered as they interacted with the health system. The purpose in doing so was to have consumer feedback inform service improvement. The Project was undertaken from October to December 2002.

### 1.2 Project Aims and Objectives

The Project aims were to assess women's experiences of their interactions with the health system. By collecting such data it was expected that it would inform the development of future improvement strategies for the Breast Services Enhancement Program.

The Project's objectives as stated in the WBSA Project Proposal were to:

- Gain a clear understanding of women's experiences of and satisfaction with services within the diagnostic pathway;
- Explore those factors that may influence women's anxiety, both factors within the system and personal coping strategies;
- Identify women's understanding of their condition and how well their information needs were met;
- Identify opportunities for future service improvements.

The data collected from consumers was to be analysed and presented to service providers to inform future service improvements.

### 1.3 Methodology

The Project proposal (September 2002) prepared by the Western Breast Service Alliance – Breast Services Enhancement Program specified “a *qualitative study to seek women’s’ views on their experiences of a breast symptom and the diagnostic and management processes.*” Consumer feedback was to be gained through up to 5 focus groups of 6 to 10 women. The focus groups were to be supplemented by up to 5 individual interviews with women from specific language groups, using interpreters. Women consumers were to be in the age range of 18 to 50 years. The focus groups and telephone interviews were to be conducted by the Project Consultants Jenny Ashby & Associates.

Recruitment of participants (women consumers) for the Focus Groups was the responsibility of the WBSA. A two step process was used.

Step 1 involved service providers obtaining initial written consent for future contact by women attending clinics who indicated an interest in participating in the Consumer Feedback Project. Women indicated on the consent form if they wished to be contacted by telephone or letter. Women were given a Project Information Sheet (see Appendix 3) to explain the Project and what was involved.

Step 2 involved a telephone invitation to participate in either a focus group or a telephone interview. The majority of women chose telephone interviews and only four women were willing to participate in the focus groups being offered in Carlton, Footscray and Sunshine.

The impact of this response from the consumer group altered the methodology in that two focus groups were undertaken by the Project Consultants in Sunshine and Footscray and fourteen individual telephone interviews were conducted. Most women clearly indicated that they preferred a one to one discussion over the telephone due to the sensitivity of the matters they wished to discuss.

However, the four women who attended the two focus groups clearly stated that they were keen to meet with other women to hear what their experiences had been. As they wanted their experiences to inform future service improvements they were prepared to spend the time in focus group discussion.

The focus group were planned for a duration of 2 hours each and having only two women at each session meant that the Project Consultants were able to explore the questions in greater detail. The richness of this data provided the material for the case studies, which have been included in addition to the contracted arrangements. The telephone interviews averaged 25 to 30 minutes each.

In all 18 women participated in the Consumer Feedback Project. These 18 women were all asked the same pre set questions by the Project Consultants (see Appendix 2).

## 1.4 Project Parameters

The Project was clearly designed to be within a quality improvement rather than a research framework. The emphasis therefore was on what the women consumers participating wanted to say using the broad areas that the Project Reference Group had identified to be explored as a guide (see Appendix 2). The 18 women participating showed remarkable consistency in their feedback as was reflected in writing up of the focus groups and telephone interviews within the key findings section of the Project Report.

The Project Consultants were mindful of the need for flexibility in reposing to the consumer's choice of focus group or telephone interview. It needs to be noted that the telephone interviews were much more time consuming than the focus groups as it required more set up time, more interview time and additional time to write up 14 individual summaries than would have been to conduct more focus groups.

Two constraints impacted on the Project. The difficulties in recruitment of participants encountered by the WBSA, which led to a delay in the timing of focus groups and telephone interviews. This meant that women were being consulted in December and by mid December it became obvious to the Project Consultants that it was becoming increasingly difficult for women to participate in the Project due to other commitments.

The Project Reference Group had indicated that 100 women would be approached by WBSA, expecting 50 to agree and realistically having 30 women participate.

However, the WBSA faced numerous challenges in recruitment and, as such, the Project Consultants were given approximately 39 women to contact. More than 65 calls were made to these candidates and the final number interviewed for the Consumer Feedback Project was 18. These figures are proportional to those expected by the Reference Group. That is, half of those approached agreed to participate.

The consistency in consumer feedback however clearly indicates the areas in which women consumers wish to see service improvements and it is the Project Consultant's view that additional participants probably would not have provided much more additional data.

## Section 2 Consultations

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### 2.1 Introduction

Eighteen women in total were consulted for the Project. All of these women were given the choice of attending a small focus group discussion or being interviewed by telephone at a time convenient to them.

Four women chose to attend focus group discussions, one held in Sunshine on Monday 2<sup>nd</sup> December 2002 at 10.00am, and the other on Thursday 5<sup>th</sup> December, 2002 at 6pm in Footscray. The other fourteen women chose to be interviewed by telephone. Most women felt that the opportunity for a telephone interview better protected their privacy and afforded them a high level of anonymity.

### 2.2 Demographics

Women participating in the consultations were asked for information about their age, number of children (if any), education, ethnicity, country of birth, language spoken at home, the service they were treated at, management of any previous benign breast problem/s and family history of breast cancer.

For a participant by participant breakdown, see Table 1 in Appendix 1.

A diverse range of women were consulted for the Project. Key demographic points included:

- The ages of women consulted ranged from 25 to 57 years
- Six women had no children, two women had one child, five women had two children each, and the remaining five women had three children each
- Seven women had completed some level of secondary education, eight had completed university, and three had studies at TAFE level
- Nine women cited their ethnicity as Australian / Anglo-Saxon, two were Phillipino, two Maltese, one Russian, one Egyptian and one Turkish
- Most spoke English at home, with other languages spoken being Russian, Phillipino, French and Maltese
- Seven women were treated at the Royal Women's Hospital, six at the Sunshine Hospital, three at the Western Hospital and two at the Royal Melbourne Hospital
- This was the first breast problem for nine of the women
- Nine women had had some form of breast problem in the past
- Most of the women with a previous problem saw their GP, had tests, saw a specialist, and had an operation to remove the lump on these occasions
- Seven of the women interviewed had some family history of breast cancer, citing family members including maternal aunt, mother, sister, maternal grandmother and paternal cousin.

For detail of the Service that the women used and the history of breast problems in participants, see Table 2 in Appendix 1.

## 2.3 Key findings from the Telephone Interviews

### Initial Response

Most women responded to discovering their breast problem with shock, panic, fear and disbelief. One woman was not surprised that her doctor found the lumps during a routine breast check, as she 'knew the lumps were there,' but had thought they were normal for her. The reasons given for the women's response ranged from the surprise and unexpectedness of finding a breast lump, to a memory of family history of breast cancer, or of other family members and partners dying of cancer of some kind.

Eight women interviewed contacted their General Practitioner's (GP's) rooms by telephone for an appointment within a week of discovering their breast lump. Three women had existing appointments with their GPs for other reasons at which their breast problem was discovered during routine breast checks. Three other women found their own lumps, but already had appointments with their GPs booked, so waited to tell their GP until then. Only one woman left it for a month before calling her GP for an appointment.

### Experience of seeing a General Practitioner (GP)

Three women did not see their GP first about their breast problems. Of these, one woman was due to give birth, so called her Obstetrician on discovering her breast lump, one just called a Breast Clinic without a referral, and one attended a hospital for a Pap Smear test and had her breast problem discovered in a routine check there. The other eleven women all saw their GP about their breast problem and were referred on from there.

Two women reported dissatisfaction with their experiences of seeing their GPs.

One woman said that her GP refused to discuss the results of an ultrasound with her, apart from informing her that she had two cysts, one that needed removal, and one that had to be aspirated. None of the questions that the woman asked her GP were answered. When the woman requested a copy of the report, she was refused.

The other woman was not informed that her GP had moved premises when she made the appointment. She said that she felt stressed about her breast problem as it was, and almost did not bother going to the new address. When she found the new premises, she had missed her appointment time, and had to wait for almost an hour to be seen. She reports that she almost left and did not get her lump checked by her doctor because of this.

Most women felt that seeing their GP was a formality in the process of dealing with their breast problem. They did not expect much reassurance or progression on their treatment from their GP. This expectation was reserved for visits to the Specialist.

GPs were mainly relied upon for preliminary information about benign breast disease, and were also often asked to facilitate the smooth transition from generalist to specialist treatment by faxing results, explaining situations over the phone and other 'smooth running' details.

### **Experience of seeing a Specialist**

Eleven out of the fourteen women interviewed found their visit to the Specialist informative and reassuring. Women's confidence returned when they felt that they were doing something about their breast problem, and especially when they received the results from any testing procedures required.

One woman, Participant M, found that she could not see her Specialist on the day that the appointment was scheduled, and had to see a different one. The Specialist who she saw also brought in a student to observe the appointment and asked her in front of the student whether she minded them being there. She said in the interview that she did mind, but that she was not comfortable refusing to have the student there, when they were already present in the room. Participant M said that this happened at two of the appointments that she went to at her treating service.

One other woman, Participant R, found that she was not told much about what would be happening to her, nor was she given enough information about her condition. This lack of information made her nervous.

Participant E arrived at her appointment with her Specialist to find that her test results had been misplaced. She was also forgotten in the queue, and waited for over two hours to be seen. Her Specialist contacted the testing Clinic and had a heated discussion with them regarding the lost results. Participant E reported that this made her feel supported by her Specialist, which contributed to her favourable assessment of her experiences.

There was a general feeling amongst the women interviewed that they would have liked more time with the Specialist to ask any questions that they had, and have them answered in an in-depth, considered manner.

### **Experience of testing procedures**

Most women complained of discomfort ranging from mild to extreme during mammograms. Some found that the attitude of the operator conducting the test helped them to deal with it, with some operators initiating a conversation with a woman to distract her from the proceedings. Many interview participants found that tests seemed more tolerable when the technicians' and operators' manner was personable. Mammograms that were conducted without conversation of some kind were perceived as more painful than those where the woman was engaged in conversation.

Ultrasounds were less difficult for women, though most women would have liked some explanation of the images appearing on the screen, and some reassurance that results would be available soon. Women who had been tested by a Radiologist rather than an Operator or Technician were more satisfied with their experiences, as the Radiologist could give them some idea of results at the time of testing. Sometimes operators and technicians were perceived as brusque, as they could not give information that some women asked for, ie: reassurance that their lumps were benign.

### **Satisfaction with the process**

Most women were satisfied with the process that they went through.

Some found that they had to wait up to a month or six weeks to see a Specialist, and that this wait impacted upon their levels of anxiety. Others had to wait up to three hours in waiting rooms to see a Specialist, and would have preferred a quicker turnaround time.

The manner of the Specialist had a large impact on women's satisfaction. Women whose Specialist spent time with them explaining test procedures and the results of testing had higher levels of satisfaction than those who felt that they did not get enough time with the Specialist.

### **Coping / Anxiety**

Most women reported very high levels of anxiety and worry in the time between seeing a GP and seeing a Specialist. The longer a woman had to wait to see a Specialist, the worse her anxiety became.

Women tended to rely on family and friends to help them cope with their anxiety, with some women also using work acquaintances as supports.

One woman, Participant C, did her own reading about breast cancer, but not about benign breast disease. No other women mentioned researching their problem as a means of reducing anxiety, but the provision of verbal information by Specialists was a factor in reassuring some women. Some women read their test result reports in an attempt to feel more informed.

Women's anxiety levels dropped dramatically once the Specialist had given them their test results. Most were still mildly concerned about the possibility of another lump occurring, and of the possibility of that lump being breast cancer, but did not rate this concern as being of an all-consuming nature.

### **Interaction with the Health System**

Women tended to wait between three days and six weeks before seeing a Specialist. The length of time they waited impacted directly on their levels of anxiety, and their ability to cope.

Fear was a factor that influenced women in their interactions with the health system in different ways. One woman, Participant F, put off her appointment with the Specialist for a year, due to fear about what might happen. During this time, she said that the Breast Clinic she was referred to rang her often to remind her to come in to see a Specialist. She was glad that they did. Now that she has been through the system, she stated that she would go again immediately if she found an abnormality in the future.

The waiting time to see a Specialist impacted on women significantly.

Women reported a feeling of being unable to function properly because of thinking about their breast problem constantly. Many said that they feared going in for tests, which may be painful, and also feared what the tests may find. Most would have liked to have seen a Specialist sooner than they did, as seeing a Specialist had such a positive impact on their anxiety levels.

## Information provision

Women were only given verbal information.

Where this information was given in a considered and inclusive manner, women found that it was enough for them. Information and results that were just “dumped” on women, with little or no explanation of medical terms and procedures were found to be confusing and not particularly helpful. The importance of a medical practitioner gauging a woman’s personality and her preference for a specific type of information was stressed in the responses that women gave.

All women commented that they appreciated, or would appreciate, a Specialist spending more time with them, answering their questions and giving them more information about their condition.

Eleven women thought that a brochure of some kind on benign breast disease would have been helpful. Two women thought that there should be more information on the Internet about benign breast disease, though one woman did find Internet information on lumpectomies and benign breast problems.

## General

Most women said that their anxiety dropped almost completely after seeing their Specialist, and / or getting their results. Only a small number of women stated that they were still as anxious as they were at the start of the process.

Things that increased women’s anxiety included :

- An abrupt manner in a Specialist, technician or operator
- A family history of cancer or breast cancer
- Being re-referred for any tests that needed to be repeated for some reason
- An unwillingness on the part of medical staff to explain or discuss result reports with women
- A difficult or unfriendly bedside manner or body language of the Specialist / Surgeon / Operator / Radiologist
- Waiting time, both between seeing a GP and a Specialist, and actually in the Specialist’s rooms
- Testing procedures that were not explained properly
- Inappropriate displays in waiting rooms, such as pictures of mothers and babies in a waiting room at a Specialist’s clinic.

When asked what one thing women would change in hindsight, they responded with comments along the following lines :

- I would have liked a different doctor, with a better manner
- I would have liked more information about benign breast disease / cysts and how they happen
- I would have liked to choose who I saw in the breast clinic
- Less time between seeing the GP and the Specialist would have been good

- Less pain in the mammogram!
- Results not getting lost
- More time with the Specialist would have been good
- Distance was a problem, as I live very far away from the hospital
- Professional explanations and reassurance, with the Specialist going through the report with the patient, and giving them the right to ask questions
- Being informed of exactly what to expect at each stage of the process would be a good thing.

### **Summary**

Women interviewed by telephone had had predominantly positive experiences in their interactions with the health system overall.

A common theme throughout the interviews, however, was that the length of time between being referred by a GP for tests and seeing a Specialist had a marked effect on anxiety levels and ability to cope in daily life. The length of time spent in waiting rooms, reported as anything from five minutes to three hours, also impacted on women's perceptions of their experiences.

Most women would have appreciated more information, both written and verbal, throughout the whole process. Many participants said they needed more time with Specialists, with the opportunity to ask questions and receive considered answers suitable to their needs. A brochure, possibly with a list of Internet sites to supplement knowledge, was the most commonly suggested way of providing additional information.

## 2.4 Key findings from the Focus Groups

The Focus Group interviews with women afforded the opportunity to spend more time gathering information. The information given at the Focus Group meetings was consequently a rich source of in-depth data on the process that each woman experienced in her interaction with the health system. The four women's stories from the Focus Groups were used in the construction of the Case Studies (see Appendix 3). The following information conveys the essence of what these women said about their experiences.

### Initial response

The four women who chose to attend a Focus Group reported that their initial responses to having a breast problem were panic and shock. One woman had her breast swell up to three times its normal size with a staph infection, which she found very alarming. One woman was attending her GP's for a Pap Smear when he did a routine breast check and found a lump. Another has a regular monthly breast check with her GP, as her breast problems are recurring. The fourth woman rang her GP for an appointment straight away.

### Experience of seeing a General Practitioner (GP)

As with the telephone interviews, most of the four women felt that seeing their GP was a formality in the process of dealing with their breast problem.

One woman felt totally supported by her GP, who made appointments with a Specialist for her and encouraged her to call him with any concerns. Conversely, another participant visited her GP as soon as possible after discovering the lump and was referred to a public hospital straight away. For this woman, seeing her GP was more of a formality in the process she had to go through.

These women's experiences indicate that as a 'front line' of interaction, GPs have great influence on how a woman approaches her breast problem, and how supported she feels throughout the process of dealing with a benign breast lump.

### Experience of seeing a Specialist

These women found that they experienced great relief when they saw a Specialist about their breast problem. All of the women agreed that the 'bedside manner' of the Specialist or Surgeon impacts on women's feelings about their condition and any planned procedures. Women tended to view seeing a Specialist as a turning point for dealing with the problem. They felt as though they were doing something proactive about their health concerns.

### Experience of testing procedures

The length of time that women waited for their test results had a great impact on their state of mind. One woman described the wait as frustrating and disheartening, and said that it made her lose faith in the system.

Mammograms were pinpointed as being the worst type of test, especially if a woman had existing scar tissue from previous biopsies.

One participant said that she has been having needle biopsies for a number of years, but had a shock one day when she was sent for another one and found that the procedure had changed. No explanation of what was going to be done was given to her at the time, and she was unable to continue with the testing procedure due to shock.

Another participant fainted when she was having a mammogram and hit her head. She was kept in the hospital for observation all day, and expressed surprise that a doctor rang her at home to check that she was ok.

### **Satisfaction with the process**

All four women were satisfied with the process that they went through. Even women who had had problematic experiences with GPs to begin with reported that once those problems were dealt with, and a considerate Specialist found, they felt confident that they were being dealt with in the best manner possible.

The women also stated that they found it very important to find a Specialist they felt comfortable with. This did not necessarily mean finding a Specialist who was a woman or who was business-like, but rather one with whom they shared a rapport.

### **Coping / Anxiety**

All of the women who participated in Focus Group discussions said that fear of the unknown impacted the most on their ability to cope. This was in particular reference to waiting for test results and their appointments with their Specialists. Fear tended to lessen once a benign result was known, but most women felt that they only felt completely free of worry after the whole process was over.

Women named networks of family and friends as their main sources of support during their interactions with the health system. Some women also spoke to people at work about what they were going through. All women found that sharing their experiences with other women who had been through the same thing helped them to feel less isolated.

### **Interaction with the Health System**

One of these women (with the staph infection) was seen by a Specialist within two days of her GP calling to make an appointment on her behalf. Another waited only four days for her appointment. The other two women waited three and four weeks respectively for their Specialist appointments. All of these women said that shorter waiting times for appointments leads to less stress for women.

## Information provision

All women were given only verbal information about their condition, and most were satisfied with the information that they were given. One woman, however, was unclear as to what was going to be removed from her breast – the whole lump, or just a piece of it for analysis. This woman also said that she did not meet the Surgeon who would be operating on her before the operation, and that this impacted on her feelings about the procedure.

Women who had operative procedures were given written information sheets about what to bring and other pre-admission procedures, and care at home after the procedure.

Two women searched on the Internet for information, but could not find any easily understandable 'plain English' sites. Both of these women thought that a piece of written information, such as a pamphlet or brochure would have been helpful to them. The other two women consulted disagreed, stating that written information had the potential to raise more questions than it answered.

## General

All of the women who participated in the Focus Groups discussions emphasised the importance of communication between patients and their carers. How these interactions occurred were the largest influencing factor in how a woman rated her experience of interactions with the health system.

Women said that practitioners should:

- Communicate sensitively, with no condescension
- Allow enough time to answer questions that women have
- Encourage women to ask questions
- Explain medical terminology, mindful of their own familiarity with these terms
- Be aware of their body language.

## Summary

Women who chose to attend Focus Groups had all had some kind of operative procedure to remove a lump from their breast. They had varying information needs, but all agreed that the attitudes of the medical practitioners attending them had a significant impact on their state of mind.

## 2.5 Summary

Women consulted tended to emphasise the need for medical professionals to recognise that they are all different, and respond to medical treatment and situations in different ways.

They called for flexibility in information provision and a sensitivity to whether information was required at particular times or not. A majority of women thought that they would have liked to be provided with a brochure on their condition, though some women expressed concern that this would take the place of verbal information and the opportunity for asking questions of their Specialist.

Most women were in agreement that the time between seeing their GP and seeing their Specialist impacted greatly on their ability to cope, and that the shorter this time span was, the better.

When asked what they would do in the event of a future breast problem, all women said that they would go through the same process as before. All of them felt that there was no other option than to do this.

## Section 3 Analysis

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### 3.1 Introduction

The analysis has been based on the key findings and themes that emerged from the consumer feedback and are reported on below. Learnings from four Case Studies, which can be found in full in the Appendix 3, are also included to give a sense of how the personal experiences of women can impact on their feelings about their treatment.

### 3.2 Implications of the Key Findings

The key findings from the Consultation process indicated that there were three main areas that need to be addressed to improve women's experiences while accessing the health system. These were:

- strategies to reduce women consumers anxiety,
- improvement in the training of and service delivery by health professionals
- improvement in information provision to consumers. Possible approaches are discussed below.

#### **Strategies to reduce women consumers anxiety**

The data gathered in the Consultations clearly indicates that there is generally a sharp rise in women's anxiety levels when any delays are experienced during their interaction with the health system. This applies to delays in obtaining an appointment with a Specialist, time spent in waiting rooms for appointments, the time between seeing a Specialist and undertaking testing procedures ordered, and the time taken for results to be available to and discussed with the woman.

In addressing this issue, the following strategies could be implemented to reduce women's anxiety :

- Reducing waiting time for the results of tests
- Improving the manner of treating health professionals, and
- Streamlining services so that there is a shorter time between referrals, tests, and follow up appointments.

#### **Strategies for improvement in the training of and service delivery by health professionals**

Many women commented that the bearing and spoken manner of the health professionals looking after them had a great impact on their feelings during the process.

Interaction with the health system could be improved for women by:

- Improving the 'respect' of practitioners for the consumer they are treating / serving
- Improving the training of health system staff to increase their sensitivity in communication with women consumers
- Improving consumer confidence in the procedures performed in the health system
- Co-locating services that are required by consumers to foster familiarity, eg: reception, testing procedures, specialists and operative procedures
- Ensuring procedures are in place to support interns involved in treating women through their checking of patients concerns with experienced medical practitioners.

### **Improvement in information provision to consumers**

Women indicated that they would benefit from more information being available to them. Some strategies to consider are:

- Ensure multiple approaches to information provision so that different consumer needs for information are met through various formats; such as:
  - Internet access and website information
  - Written information
  - Alternative therapy information
  - Verbal information, and reinforcement of such information
  - Nutrition and specific diet information for better health, (and, if available, condition specific dietary requirements)
- Information content for consumers needs to include:
  - health condition(s), possible causes, available treatment, procedures, processes
  - How various treatments will affect the consumers' personal lives, possibly presented in the form of scenarios / case studies.

### **3.3 Learnings from Case Studies**

Four separate Case Studies were developed from the data gathered from the Focus Group discussions. Each told a woman's story from her own perspective, allowing different aspects of their collective feelings about their progress through the health system to emerge. The full-length Case Studies can be found in the Appendix 3. Below are listed the main points learned from each of the women's stories. These necessarily repeat the key findings from the telephone interviews, but are particularly useful when read as part of a Case Study, which personalises the experiences that are written about.

**Case Study 1**

From Sarah's Case Study we have learnt that consumers want:

- A short wait in knowing the outcomes of any testing, as this reduces their anxiety – therefore there is a need to streamline and quicken the procedures to be undergone to obtain a faster diagnosis
- Treatment and care from medical practitioners and other health staff who are compassionate and have a good “bedside manner,” as the way consumers are treated in their interaction with the health system has a great impact on their levels of anxiety.

**Case Study 2**

From Mary's Case Study we have learnt that consumers want:

- Flexibility within the health system to accommodate different consumers' needs with regards to information provision and the manner in which they are dealt with by staff in the health system
- Sensitivity in communication. This applies to all medical practitioners involved in a consumer's interactions as they progress through the health system.

**Case Study 3**

From Rachel's Case Study we have learnt that consumers want:

- To be respected by the practitioners treating them, whatever the consumer's age, social, marital or educational status
- Confidence in the health system with regard to procedures being performed. Consumers would like more transparency of procedures, assurance that all is going to plan, and the follow-through to ensure that it does.

**Case Study 4**

From Josephine's Case Study we have learnt that consumers want:

- More information, firstly about their condition, possible causes and treatments, and secondly about how their treatment could affect their personal lives
- A more streamlined service, resulting in less time spent in waiting rooms, and a shorter time between referrals, tests and follow-up appointments
- Continuity of staff and procedures in one geographical area of the hospital. For example, having reception, testing procedures, specialists and operative procedures in the one area to foster familiarity for consumers
- Care from informed and experienced medical practitioners, with a provision that if care is provided by an intern, there is a procedure in place that enables them to follow-up with a patient and provide them with information if they are unable to answer questions on the spot.



# Appendices

**Appendix 1 Table 1 and Table 2**
**Table 1 Demographics of Participants in Telephone Interviews and Focus Groups**

<i>Participant</i>	<i>Age</i>	<i>Suburb</i>	<i>Children</i>	<i>Education</i>	<i>Ethnicity</i>	<i>Country Of Birth</i>	<i>Language</i>
<b>H</b>	37	Footscray	0	University	Anglo	Australia	English
<b>D</b>	34	Altona North	1	Secondary	Anglo	New Zealand	English
<b>E</b>	41	St Albans	3	Secondary	Australian	Australia	English
<b>S</b>	42	Ardeer	3	Secondary	Australian	Australia	English
<b>J</b>	39	Aspendale Gardens	2	University	Russian	Russia	Russian
<b>K</b>	30	Brunswick	0	University	Australian	Australia	English
<b>G</b>	51	Keilor East	3	Secondary	Australian	Australia	English
<b>B</b>	47	Wyndham Vale	0	University	Phillipino	Phillipines	Phillipino
<b>M</b>	25	Hoppers Crossing	2	University	Australian	Australia	English
<b>F</b>	42	Sunbury	1	University	Asian	Phillipines	English
<b>C</b>	57	Flemington	0	University	Australian	Australia	English
<b>R</b>	41	Gowanbrae	0	University	Egyptian	Cairo	French
<b>N</b>	35	Meadow Heights	3	Secondary	Turkish	Turkey	Australian
<b>P</b>	41	Meadow Heights	2	TAFE	Maltese	Malta	English
<b>I</b>	43	Sunshine West	3	Secondary	Maltese	Malta	English / Maltese
<b>A</b>	40	Altona Meadows	2	Secondary	German	Australia	English
<b>O</b>	44	Nth Fitzroy	2	TAFE	Anglo	New Zealand	English
<b>Z</b>	25	Maiden Gully	0	TAFE	Australian	Australia	English

**Table 2 Service used and history of breast problems in Participants**

<i>Participant</i>	<i>Treating Service</i>	<i>First breast problem ?</i>	<i>Time of previous problem</i>	<i>Management of previous problem</i>	<i>Family History of Breast Cancer?</i>	<i>Family member with history</i>
H	WH	Yes			No	
D	SH	Yes			No	
E	WH	Yes			No	
S	SH	No	5 years ago	Saw GP, had tests, saw specialist, had operation to remove	Yes	Maternal Aunt
J	RWH	No	10 years ago, in Russia	Had tests	No	
K	RWH	Yes			No	
G	SH	No	20 years	Saw GP, had tests, saw specialist, had operation to remove	Yes	Mother, maternal aunt
B	WH	Yes			Yes	Sister
M	SH	Yes			No	
F	SH	Yes			No	
C	RWH	No	10 years	Saw GP, had tests, saw specialist	No	
R	RWH	No	6 years (1997)	Saw GP	Yes	Maternal Aunt, Paternal Cousin
N	RWH	Yes			Yes	Maternal Grandmother
P	RWH	No	15 years, in Malta	Saw GP, Surgery straight away, Saw Specialist	Yes	Maternal Aunt
I	SH	No	2000 & 2001	Had operation to remove	No	
A	RWH	No	Oct 2002, Sept 2001, July 1996	Saw GP, had tests, saw specialist, had operation to remove	Yes	Aunt
O	RMH	No	Dec 2001	Saw GP, had tests, saw specialist, had operation to remove	No	
Z	RMH	Yes			No	

**Key : WH – Western Hospital, SH – Sunshine Hospital, RWH – Royal Women’s Hospital, RMH – Royal Melbourne Hospital**

## Appendix 2 List of questions and participant profile used in Focus Groups and Telephone Interviews

### Consultation Questions

#### Process

- What was your initial response to your breast problem ?
- Who did you first make contact with regarding your breast problem ?  
How did you go about doing this ?  
When did you do this ?

*Prompt : For example, the day you found the problem, a week later, etc.*

- What were your experiences of :
  - a) seeing your local doctor ?
  - b) any testing procedures you went through ?
  - c) your visit to the specialist clinic ?
  - d) any other tests you may have had ?

*Prompt : How easy for you was it to make appointments ? What, if anything, could have made it better ?*

- Were you satisfied with the manner this was dealt with ?
- How did you cope when you discovered your breast problem ?

*Prompt : What happened when you were waiting, between discovering your breast problem and seeing your doctor or Breast Clinic specialist ?*

#### Interaction with the Health System

- How long did you have to wait to see a specialist ?  
Did this wait impact on you ? How ?  
What sort of impact did this wait have on you ?
- How were you informed about your condition and what would be happening to you ?

*Prompt : What kind of information were you given ? (written, verbal) ?*



*Is there any other form of information that would have been more helpful ?  
(eg : email, website, flyers)*

Did you feel this was done well / adequately / poorly ?

- What, if anything, did you know about breast problems before this situation occurred ?
- Was the information you were given adequate ?

*Prompt : If not adequate, why not ?*

- Did you get the information at the time you needed it ?
- What were your impressions of your contact with :
  - a) your GP ?
  - b) radiology services
  - c) having a needle biopsy or operation
  - d) Breast Clinic nursing / medical staff
- How much, if at all, has your anxiety dropped since seeing the specialist ?  
What, if anything, are you still anxious about ?  
What would you do if you had a breast problem in the future ?

### **Personal Privacy**

- Did you feel that you were respected during the process you went through while finding out about your breast problem ?

*Prompt : What did not work well ? How could this be improved ?*

### **General**

- From your experience, what things helped to reduce your anxiety ?
- What things happened to increase your anxiety ?
- With the benefit of hindsight, what one thing would have made a difference to your experience ?



### Participant's Profile

These questions are designed to give us general background information to help us collate the responses that you have given us today. All of the information that you have given us is confidential, and no information has been asked for that will identify you as having participated in this research. If you are uncomfortable with any of the questions that we ask you in the following section, you do not have to answer them.

However, any information that you do choose to give us will be very valuable, helping us to better understand your opinions.

**Age :**

What is your age ? \_\_\_\_\_

**Location :**

Which suburb do you live in ? \_\_\_\_\_

**Children :**

Do you have any children? (please circle)      Yes      No

If yes, how many? \_\_\_\_\_

**Education :**

What is the highest level of education that you have completed ? (please circle)

Primary      Secondary      University      TAFE      Trade

Master's      Doctorate (PhD)

Other (please specify) \_\_\_\_\_

**Ethnicity :**

What is your ethnicity ? \_\_\_\_\_

What country were you born in ? \_\_\_\_\_

What language do you speak at home ? \_\_\_\_\_

**Symptom Management :**

Which service / hospital were you treated at ?

\_\_\_\_\_

Was your recent breast problem your first breast problem ? Yes    No

If no, when was / were your previous problem/s ? (please specify month and year)

\_\_\_\_\_

How were these previous problems managed ? (circle as many as relevant)

Went away    Saw GP    Had tests    Saw specialist    Had operation to remove

Do you have a family history of breast cancer ? (please circle) Yes    No

If yes, who in your family has had breast cancer ? \_\_\_\_\_

## Appendix 3: Case Studies

Four Case Studies have been developed using material gathered in the Consultation process. These help to personalise the data that has been put together from the interviews, and to illustrate different ways that women have progressed through the health system, their impressions of their treatment and their state of mind at different stages of their treatment.

### Case Study 1: Sarah's Story

Sarah is a 40 year old Australian woman of German ancestry. She is married, with 2 children, and has completed secondary education. She has had recurring benign breast problems since July 1996, with recent episodes in September 2001 and October 2002. Her maternal Aunt has had breast cancer. She has noted that her breast problems always occur at around the same time of year.

#### Sarah's interaction with the Health System

Sarah performs a monthly breast check on herself. When she found problems in the past, she always called her local doctor (General Practitioner – GP) for an appointment, who then referred her to a Specialist.

#### Sarah's Initial response

Sarah usually called her GP within two days of discovering a lump in her breast. After this, Sarah had testing procedures including mammograms, needle biopsies and ultrasounds. Her breast problems were always diagnosed as benign.

#### Experiences of the medical system

**GP:** Sarah goes to a GP who she has confidence in, and who she feels comfortable visiting or calling on the telephone. She said that she had the same GP for 20 years, and had to find another one recently when her long-time GP retired from practise.

The last breast problem that Sarah had occurred in October 2002. She was due for a Pap Smear test, and had already found a small lump in her breast before her appointment.

She did not tell her doctor about the lump, as she wanted to see if the doctor would pick it up in the routine breast check that was performed. Her GP did not pick up the lump, so Sarah showed her doctor where the lump was located. She was immediately referred to a Specialist and sent for x-rays and other diagnostic tests within the week.

*is important in fostering trust in the practitioner. This is especially important because procedures often feel like an invasion of our bodies."* Sarah

**Testing procedures:** Sarah was referred to have a mammogram, a needle biopsy, an ultrasound and a blood test. She found her mammogram very uncomfortable, and over time has discovered that tension during the procedure makes the discomfort worse.

The needle biopsy procedure has changed over the time that Sarah has been having them. When she first began having them, fluid was taken from a lump in her breast. The last time that she had a needle biopsy, she found that the procedure had changed - a tissue sample was taken by needle, which caused a lot of pain and bleeding. Sarah was not informed of the change in procedure, and had not expected there to be any bleeding at the site of the needle stick at all. She was supposed to have needle biopsies on two separate lumps that day, but was unable to continue with the procedure after the first biopsy was taken, due to her shock and the distress caused by her unexpected bleeding.

**Visits to the specialist clinic:** Sarah is glad to be seeing the Specialist she is, but would question whether gender (ie: female practitioner) would be an issue in whom women choose to see. She finds her Specialist very compassionate, and less 'business-like' in manner than some of the other medical people with whom she has had contact. Sarah wonders whether some Specialists cultivate a brisk business-like manner to seem more professional. She emphasised that she prefers someone she can talk to, and who is prepared to give her the time needed to answer her questions and allay her concerns.

**Making appointments:** Making appointments has always been easy for Sarah. Every time she has had to go to a specialist, she has been able to arrange an appointment within a week of telephoning. The second and subsequent times that she found breast problems, Sarah just rang the Specialist straight away, as she was still covered by her GP's referral letter. Sarah found that even with a relatively short wait for a Specialist's appointment, she still had underlying nagging doubts and anxiety about whether her breast problems were benign or malignant.

**Coping:** Networks of friends and family helped Sarah cope with the time between discovering her breast problems and the diagnosis. She said that she did not know how she would have coped without these support networks. Fear of the unknown was the biggest stress factor. Sarah reported that every time she was told a benign diagnosis, her anxiety levels dropped significantly. However, in the back of her mind she still always has the statistic that 1% of lumps are cancerous.

With one of her lumps, Sarah did not have it out for over a year after it was discovered. She reported an increased level of anxiety over that year, particularly when she had her six-monthly check up.

Sarah said that, in her experience, women rely on 'word of mouth' to recommend services and Specialists with whom they feel comfortable. For example, Sarah's sister in law found a breast lump, but was too scared to go to her GP, "in case it was something serious". Sarah spent some time talking to her sister in law, convincing her that it was in her interests to seek medical advice. The woman eventually went to see her GP, and was diagnosed with breast cancer, which responded well to treatment.

*"Explanations from Specialists after both negative and positive events take place help women to cope with them."* Sarah

**Information:** All the information that Sarah was given in her interaction with the health system was verbal. She did not ask very many questions, but was given good answers when she did think of things to ask. She feels that no other form of information would have helped her to cope, as she prefers face-to-face contact with people. She also said that sometimes written information can raise more questions than it answers and therefore causes unnecessary concern / hardship until clarification can be sought.

**Privacy:** Sarah felt that her privacy was well respected during all of the procedures that she went through during her experiences with the health system.

**Improvements:** Sarah feels that there should be more publicity on the benefits of early intervention aimed at women finding breast problems. She felt that women did not often make the time for appointments because they felt that they had large time commitments to their families that they could not escape. Sarah suggested information aimed at these women should be in the context of them finding time for an appointment precisely because others (ie: their families) needed them to be healthy and well.

Sarah also felt that there should be less waiting time for appointments and for results of testing procedures. She suggested that if there were a way to receive results over the phone instead of waiting for an appointment to hear your results, this would significantly reduce anxiety levels.

Sarah suggested that information about changes to procedures be made available to patients, to prepare them for what they will encounter.

**Prior knowledge:** Before her own experiences, Sarah knew that breast problems happened generally, therefore she always made a point of regularly self-checking her breasts.

**Current state of mind:** Sarah still occasionally worries about the possibility of cancer, and that her benign breast lumps will become more numerous. She describes this as a constant nagging feeling in the back of her mind. She also reports that she is now more aware of that part of her body, and takes more of an interest in her health in relation to breast care. On finding a breast problem in the future, Sarah said that she would follow the same process as she has done based on her past experience.

#### **What have we learnt from this Case Study?**

From Sarah's Case Study we have learnt that consumers want:

- A short wait in knowing the outcomes of any testing, as this reduces their anxiety – therefore there is a need to streamline and quicken the procedures to be undergone to obtain a faster diagnosis
- Treatment and care from medical practitioners and other health staff who are compassionate and have a good “bedside manner,” as the way consumers are treated in their interaction with the health system has a great impact on their levels of anxiety.

## Case Study 2: Mary's Story

Mary is 43 years old, and was born in Malta. She speaks Maltese and English at home, and is married with three children. She has completed secondary education, lives in Sunshine West. She has had recurring benign breast problems, with episodes in 2000, 2001 and 2002. She does not have a family history of breast cancer.

### Mary's interaction with the Health System

Mary noticed a sudden change in one of her breasts. It became red, and swelled up to three times its normal size.

#### Initial response

Mary immediately called and made an appointment with her local doctor (General Practitioner – GP). He diagnosed a staph infection, which he thought they could treat with non-penicillin antibiotics, as Mary is allergic to penicillin. After two days, the swelling and redness worsened, and Mary contacted her GP again. Her GP immediately referred her to a Surgeon, who informed her that they would need to remove the infection surgically. Mary also had referrals to the menopause clinic, and to a Breast Clinic.

Mary said she felt panic-struck as these symptoms happened. As well as her breast swelling, she was also worried about her allergy to penicillin, and the possibility that without it, the infection could spread to her blood, and she thought she might die.

#### Experiences of the medical system

**GP:** Mary found her GP to be extremely helpful. He asked her whom she would like to be referred to, so she was able to choose her Specialist.

**Testing procedures:** Mary always found mammograms uncomfortable, but now reports that, with scar tissue from a number of previous lumpectomies, they are unbearably painful.

**Visits to the Specialist clinic:** Mary found the Breast Clinic and the Hospital very supportive. Her Surgeon was very supportive, with a demeanour that she described as wonderful, which surprised her, because she thought Specialists would be brusque. Mary had had breast problems before, and those lumps had been removed operatively. Her prior experiences had not been positive, with Specialists and Surgeons appearing aloof and off-hand. Some medical practitioners she dealt with also made stray comments that they then did not explain. This in turn affected Mary's anxiety levels and ability to cope.

*"One technician, on completing an ultrasound on one of my breasts, then said, 'OK, now for the other bloke.' I couldn't believe how inappropriate that was." Mary*

**Making appointments:** Mary's GP made all of her appointments with Surgeons and Specialists for her, which she felt diminished the stress she was feeling. A Specialist saw her within 24 hours of her GP making an appointment.

**Coping:** Mary relied on her partner and mother in particular for support. She also felt that keeping in touch with networks of friends were an important part of coping for her. She reported feeling sheer panic throughout the whole experience, from her initial diagnosis to the removal of the infection. Mary was glad to be able to choose her Specialist, as she feels that her previous negative experiences had impacted on her attitude to future surgery. Before her most recent instance of breast problems, Mary had experienced extreme complications with previous surgery, but due to good management and explanations by the Surgeon at that time, she felt better able to cope and process her experiences.

Mary also feels that the "bedside manner" of the Surgeon or Specialist is most important in helping a woman cope with the procedures that she is going through. She feels this should include how carefully a Specialist words their explanations.

*"Compatibility with your practitioner's personality, rather than gender, is the most important consideration." Mary*

**Information:** Mary felt "pretty well" informed of her condition, because she asked a lot of questions of both her GP and her Specialist. Both of these practitioners were happy to spend time answering her questions. All of the information that Mary was given in her interaction with the health system was verbal. She did not feel the need for written information, as she feels that "pieces of paper can't answer questions that arise from reading them".

Mary felt that she was given all of the information that she needed at the time she needed it in her dealings with the health system.

**Privacy:** Mary felt that her privacy was respected completely throughout all of the recent procedures that she has undergone.

**Improvements:** Mary said she would prefer being seen by a Radiographer instead of a Technician or Operator when she had ultrasounds / mammograms. She felt that a more qualified person in these circumstances could give better information and reassurance. She has also found Technicians and Operators to be less communicative, more dismissive and more condescending in their attitudes to patients than the Specialists.

Mary also suggested that Specialists and doctors think about how they communicate with patients, and consciously use sensitivity when speaking. She found many Specialists overly condescending.

One suggestion that Mary made was that all patients' needs should be assessed on an individual basis. She pointed out that everyone's needs were different, including their need for information, their expectations of procedures

and the manner in which they are dealt with. She said that flexibility on the part of the health system was one of the most important aspects in dealing successfully with a range of patients with different needs.

**Prior knowledge:** Mary had been self-checking her breasts, knowing that this was necessary for all women in order to pick up breast changes early.

**Current state of mind:** Mary says that she feels “a lot tougher now” psychologically, and knows that there can be a positive resolution to most things, if they are discovered and dealt with quickly enough. She still worries about getting another staph infection, and whether she will experience more benign or malignant breast problems in future.

Mary said she would follow the same steps for dealing with a breast problem in future.

#### **What have we learnt from this Case Study?**

From Mary’s Case Study we have learnt that consumers want:

- Flexibility within the health system to accommodate different consumers’ needs with regards to information provision and the manner in which they are dealt with by staff in the health system
- Sensitivity in communication. This applies to all medical practitioners involved in a consumer’s interactions as they progress through the health system.

### Case Study 3: Rachel's Story

Rachel is a 25 year old woman from Bendigo. She was born in Australia, has completed a TAFE qualification and has no children. She recently experienced her first breast problem.

#### Rachel's interaction with the Health System

##### Initial response

Rachel was originally booked in for an appointment with her local doctor (General Practitioner – GP) for a routine Pap smear test. The doctor also performed a breast check, and found a lump. Rachel said that she was shocked at the discovery of the lump, and immediately felt panic.

##### Experiences of the medical system

**GP:** Rachel said that her GP made light of and laughed at her shock, then referred her for an ultrasound. Not feeling comfortable going back to her local doctor, Rachel had the ultrasound done, and made an appointment with a different GP to go over the results.

She felt that her experiences with the second GP were not much of an improvement on the first. She reports that this GP seemed eager to “palm her off” because she is young, and told her not to worry about the lump, and to, “stop complaining.” She felt that this treatment made her lose confidence in the local doctors.

A friend of Rachel's father said that he had heard that the Breast Clinic in Melbourne was very good, so Rachel obtained a referral to a Specialist there.

**Testing procedures:** Before her doctor discovered her lump, Rachel had experienced a discharge from her breast, so had had a Prolactin test. The level of prolactin found was normal, so her GP wanted to send her for a mammogram. She had a mammogram and was told that her results were normal and that she would need no further tests.

When Rachel attended the Breast Clinic, she had a Fine Needle Aspiration, the results of which were also normal. She then had a Frozen Section Test, the results of which indicated that Rachel would have to have the lump taken out.

*“Seeing my specialist was a turning point – if anyone knows anything, he will!”* Rachel

Rachel commented mainly on the stress caused by having so many different procedures done, and the anxiety she felt waiting for the results of each set of tests.

**Visits to the Specialist Clinic:** Rachel found that attending the Breast Clinic was a more positive experience than her Bendigo appointments. She felt immediately reassured after her appointment with her Specialist, as she felt she had expended a lot of energy worrying about possible outcomes before talking to the practitioner. She reports that she even looked forward to having her breast lump removed, as it felt like she was finalising something.

**Operative procedures:** Rachel was nervous and did not know whether the Surgeon was going to remove part of or all of the lump. She was also concerned, because the Nurses preparing her were also unsure. Her operating theatre was suddenly changed, with only some of the Operating Team being informed. This resulted in her Surgeon being late. Rachel did not feel confident that her procedure would be problem-free.

**Making appointments:** Rachel had to wait 4 weeks before seeing her Specialist at the Clinic.

**Coping:** Rachel found the wait for test results frustrating and disheartening. She reported spending some days feeling fine, and others feeling 'flat'.

Rachel said that she has a very open family, and that she could not imagine how she would have coped without their support. She also found that once she began talking to people other than her family about her experiences, it encouraged others to tell her about their own benign breast problems and how they dealt with them.

Rachel also said that at the one-week check-up she found it valuable to see the familiar faces of patients who had also had operative procedures on the same day as hers. She said that there was a bond between patients through their shared experience.

**Information:** Rachel tried looking for information on the Internet. She found some web sites that outlined different breast problems and the technology that was used to diagnose and treat them. She stated that she would have liked to receive a pamphlet on benign breast problems and their treatment.

Rachel was given an information sheet detailing the procedure that she would undergo, though she felt that this was more focussed on pre-admission procedure, what to bring to the hospital and care after discharge, rather than on informing her of her condition.

**Privacy:** Rachel felt that her privacy was maintained throughout her experiences with the health system, but that her interactions with her local doctors were marked by a lack of respect for her as a patient needing reassurance and information.

*"The GP from the Hospital called me at home to follow up my results with me. That was unexpected, and caring for a doctor."*  
Rachel

**Improvements:** Rachel would have liked a lot more information about benign breast disease and the steps that she could take to decrease her chances of developing another lump. Information on diet, alternative treatments and current research would have been welcome.

**Prior knowledge:** Rachel had no prior knowledge about the possibility of developing breast problems, and was not performing checks on her own breasts.

**Current state of mind:** Rachel says that she is not as anxious as she used to be, but that the experience is always at the back of her mind. She said that she asked her Specialist what to do in the future if she finds a lump, and that her Specialist told her to just call and make an appointment at the Breast Clinic straight away. Rachel intends to do this in the event of discovering a new breast problem.

**What have we learnt from this Case Study?**

From Rachel's Case Study we have learnt that consumers want:

- To be respected by the practitioners treating them, whatever the consumer's age, social, marital or educational status
- Confidence in the health system with regard to procedures being performed. Consumers would like more transparency of procedures, assurance that all is going to plan, and the follow-through to ensure that it does.

## Case Study 4: Josephine's Story

Josephine is a 44 year old woman who lives in North Fitzroy. She was born in New Zealand, has 2 children and has completed a TAFE qualification. She has had one previous instance of benign breast disease, in December 2001. Her most recent problem dates from September 2002. She has no family history of breast cancer.

### Josephine's interaction with the Health System

#### Initial response

Josephine said she felt very business-like when her lump was discovered. She had an appointment for a routine Pap Smear with her local doctor (General Practitioner – GP), when he discovered her lump in a breast check. He then referred her to a Breast Clinic. She experienced a delay of about 2 weeks for her ultrasound, and arranged for her mammogram to be performed at a Hospital. This waiting time made her very nervous.

#### Experiences of the medical system

**GP:** Josephine said that her GP immediately referred her to a Specialist. She did not expect much more interaction or information from him.

**Testing procedures:** Josephine waited 2 weeks before she could have an ultrasound, and was very nervous during this time. The ultrasound was performed on a day that was 42°C. Josephine felt very overheated, and fainted when she had the mammogram. As she fell, she hit her head, and was kept in the hospital for the rest of the day under observation. She stated that the Doctors and Nurses were all very good to her after her fall, though she suspects that they were just worried about possible litigation. After she got home, one of the Doctors called her at home to make sure that she was OK. Josephine said that she was very surprised by this level of care / interest.

Josephine also had a Fine Needle Aspiration. Her Specialist recommended that she have the lump removed in case it caused pain later on – for example in a future pregnancy.

*“Women try to be rational and reassure themselves that it is just a cyst, that they are young, that it is not cancer...but you end up thinking the worst.”* Josephine

**Visits to the Specialist clinic:** Josephine said that being in the waiting room at the public Hospital was like being among “cattle in a barn.” She had to wait 1 1/2 hours for her appointment, and found the reception staff quite rude.

She felt shocked when the Specialist informed her that she had a suspicious lump in her breast that would have to be taken out. She said that she was unprepared for this diagnosis, as she had been told at her ultrasound and mammogram that the lump was probably a cyst and nothing to worry about.

**Operative procedures:** Josephine found the biopsy “most disconcerting.” She did not see her Surgeon before the operation, and reports that after the surgery she was put into a “Day room” where there were many other people waiting. When she came out of the anaesthetic, Josephine felt like there were older men looking at her. The men were there for reasons other than breast problems, and were not partners of people who were having procedures on their breasts. This made Josephine very uncomfortable. She tried to get up to go to the bathroom and almost fainted. Josephine’s mother had come with her to offer support, and made her sit down.

Josephine was looked after by an intern after her procedure. She said that the intern seemed quite young, with not a very good manner, but she acknowledged that young doctors have to learn their profession somehow.

**Making appointments:** Josephine had to wait 2 weeks to see a Specialist at the Hospital, and then another 2 weeks for her testing procedures. She reported being very anxious during this time. She feels that her anxiety could have been allayed by having appointments that were not so far apart.

**Coping:** Josephine relied on family and friends to help her cope. She spoke to a friend at work whose sister-in-law had a benign breast problem and was reassured by her story.

**Information:** Josephine would have liked more information about benign breast problems. She felt that breast cancer is given a lot of publicity, and that more could be done to reassure women who have benign conditions.

Josephine asked one Nurse who was looking after her for information on what she could change about her diet to reduce her chances of another lump developing. The Nurse did not respond directly to the question, and appeared not to know.

This prompted Josephine to search for information on the Internet. She found that most sites she accessed were jargonistic and American. She could not find a ‘plain English’ site that had information on benign breast disease.

Josephine would have liked to receive a pamphlet on her condition.

**Privacy:** Josephine felt that her privacy was not respected as much as it could have been because of her experiences after her lumpectomy. She felt as though she was in a room full of people who were there for reasons other than breast-related procedures, and as though she was on show.

**Improvements:** Josephine suggested that GPs or Specialists provide a list of references (eg: internet sites, research articles available in public libraries) that patients can look up, as health care professionals do not have a lot of time, but need to ensure that patients can personally process what is happening to them.

She also recommended that student interns be coached regarding their bedside manner and body language, as this has a large impact on a patient's state of mind.

**Prior knowledge:** Josephine said she knew nothing about benign breast disease before her experiences, except that she had to check her breasts for lumps regularly.

**Current state of mind:** Josephine said that she does worry from time to time about getting another lump, especially when the site of her operative procedure causes some discomfort. She reports feeling concerned about this discomfort, as she experiences tenderness during sex, but was given no information about this at all, and is not comfortable bringing it up with her doctor.

She said that she would go back to her GP and then to her Specialist if she found another lump in her breast.

#### **What have we learnt from this Case Study?**

From Josephine's Case Study we have learnt that consumers want:

- More information, firstly about their condition, possible causes and treatments, and secondly about how their treatment could affect their personal lives
- A more streamlined service, resulting in less time spent in waiting rooms, and a shorter time between referrals, tests and follow-up appointments
- Continuity of staff and procedures in one geographical area of the hospital. For example, having reception, testing procedures, specialists and operative procedures in the one area to foster familiarity for consumers
- Care from informed and experienced medical practitioners, with a provision that if care is provided by an intern, there is a procedure in place that enables them to follow-up with a patient and provide them with information if they are unable to answer questions on the spot.



## Appendix 4 Project Information Sheet

### Consumer Information Sheet for Consumer Feedback Project – Breast Services Improvement Project

#### What is this Project about? And who is doing it?

The project seeks to obtain consumer feedback to inform improvements to services for women who have presented with breast related symptoms in the Western Region of Melbourne. The project is from October to December 2002.

This project's aim is to assess your experiences of and satisfaction with assessment and diagnostic processes within the Western Breast Services Alliance (WBSA). This will in turn inform the development of future service improvement strategies.

Jenny Ashby and Associates are the appointed Consumer Research Team for the WBSA.

#### How will we ask women for their views in this Project?

If you agree to participate, you will be asked to either attend a small focus group, or we can make an appointment for a telephone interview at a time convenient for you.

We want to talk with women from a range of different backgrounds including women from various language and cultural backgrounds. Interpreters will be used when requested by women participants.

The focus groups will be held in local community and/or hospital settings that are as convenient as possible for you to attend. You will be paid \$40 for your participation to help reimburse for any travel costs or assist with other costs, eg. childcare.

In the focus groups and the telephone interviews we will ask you about:

- Your experiences with various health providers
- Your feelings on discovering your breast problem
- What you found to be helpful / unhelpful when you were dealing with doctors, clinics, x-ray clinics, etc

Your comments will be written down by the interviewer and / or another team member.

#### Participation is voluntary

Your participation in this project is voluntary. You are not obliged to take part. If you decide to take part and later change your mind, you are free to withdraw.

Your decision whether or not to participate in this project will not affect your care in any way.

If you agree to take part in a focus group, you will be asked to sign a consent form when you attend. If you undertake an interview, you will be asked to give your consent over the phone.

#### Confidentiality

Any information that you give to us will be documented in a way that makes sure individual women and their responses cannot be identified.

To meet Health Information requirements all information from this project will be kept in a locked filing cupboard in the WBSA project office and then in the Department of Surgery at the Royal Melbourne Hospital for a total of seven years.

#### What do we want from this Project?

As a result of this project, a report will be written based on the information provided by women through the focus groups and interviews. Recommendations for future service improvement will be made based on your feedback as consumers.

A summary of the research findings will be available to participants. If you would like a copy, please let us know by faxing or phoning your details to Jenny Ashby and Associates. Your contact details will be shredded after we post out to you a copy of the research findings.

**Jenny Ashby & Associates: Phone & Fax 9372 0380  
Email: Ashby@bigpond.com**