

PERSONAL CARE RECORD

Evaluation Report



North Eastern Metropolitan and Barwon &
South Western Breast Services
Enhancement Programs



Acknowledgements

The personal care record was developed through extensive consultation with women who have experienced breast cancer and with input from breast surgeons, radiation oncologists, medical oncologists, breast care nurses, oncology nurses, social workers, general practitioners and BreastScreen Victoria staff. Their contribution is gratefully acknowledged.

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Background

In late 1999, the North Eastern Metropolitan Breast Services Enhancement Program undertook a mapping exercise aimed at identifying gaps in the processes and systems that existed for the management of breast disease in the region. One of the findings of the exercise was that consumers had an identified need for a personalised, written record of their disease and management. Clinicians were also seeking a way of ensuring that up-to-date information about each woman was readily available as they moved between treating clinicians and institutions throughout the treatment experience.

To address these identified gaps, special project funding was obtained from BreastCare Victoria, Department of Human Services to develop a *Universal Medical Record*. The record was to include a treatment plan and would remain the property of the woman. During the development phase, the name changed to *Personal Care Record* at the request of the members of the Consumer Advisory Sub-committee who made a large contribution to its development.

Introduction

The personal care record is an organised recording booklet that is kept by consumers. The aim of the personal care record is to enable consumers to be more involved in the information recording process during their care with breast services. The record also includes general information relating to the treatment of breast disease as well as specific information that is relevant to their individual care. The personal care record has been developed as a direct result of consumer requests.

Initially developed as a project of the North Eastern Metropolitan Breast Services Enhancement Program (BSEP), the personal care record was later trialed in both the North Eastern and Barwon & South Western BSEPs. This report presents the evaluation findings from that trial.

The evaluation was conducted using three surveys that were completed by consumers after using the personal care record for three, six and ten months. Feedback from health professionals working in a range of hospital settings was also sought as a part of the evaluation process.

While the evaluation surveys were distributed at both sites this report does not aim to make comparisons about the way the personal care record was used at each of the sites. Small differences that were noticed between the two sites will be reported but the overall emphasis of this report is to detail the evaluation results, with particular emphasis on the value of the personal care record, the most effective time for introducing it to consumers, as well as consumers' and health professionals' attitudes to the personal care record.

Literature Review

The ideal of consumer participation in health and the use of personal care records (also known as hand held records or patient held records) is not a new phenomenon and these principles are embedded in many national and international health directions. The Alma Ata Declaration (WHO, 1978), the Ottawa Charter for Health Promotion (WHO, 1986) and the Australian National Health Strategy (1993) all propound that people have the right to participate in the planning and implementation of their health treatment and care. The main focus of this literature search is to examine the goals of introduction of a personal care record, including the benefits and negative impacts, as well as the important principles for consideration and the contents of the records discussed in the literature.

Why introduce a personal care record?

The *Clinical practice guidelines for the psychosocial care of adults with cancer* (National Breast Cancer Centre and National Cancer Control Initiative, 2003) state that Level II evidence shows that ‘patient held records are beneficial for patients’, and Level IV evidence shows that they have ‘considerable medico-legal benefits, such as documentation of doctor-patient communication, with no substantial practical drawbacks’ (p. 79).

The major goals in the development and promotion of personal care records, as cited by the Health Improvement and Modernisation Program (2001), Johnson (2001), and Coffey and Morris (2003) include:

- Assisting consumer participation in the planning and implementation of their health care
- Improving communication and access to patient information
- Saving time for clinicians
- Reducing the repetition of investigations
- Improving both physical and psychosocial care as well as continuity of care.

Assisting consumer participation

Personal care records can assist consumer participation in health by providing information about the individual's health/illness, their treatments, the treatment team as well as details of the person's appointments. In addition, personal care records may provide space for the patient to journal or to write questions. Access to this type of information not only facilitates greater interaction with the person's treating clinicians, but also provides a sense of increased control through increased knowledge (Johnson, 2001).

Increasing communication and access to patient information

The literature reviewed described the interaction benefits arising from the use of personal care records. Benefits include assisting communication between consumers and clinicians as well as between clinicians. An added benefit is that the personal care

record can provide a constant source of information to the consumer. The Health Informatics Association of New South Wales (HIANSW) released a discussion paper on patient held medical records in 1993. The paper outlines the cost, benefits and technical feasibility of personal care records as well as the positive benefits of patient ownership, access to and control of information. It also broadly described the main benefits as increased access to patient information and better information flow.

The Health Improvement and Modernisation Program (2001) cited the benefit for patients as being able to carry current treatment information with them in a personal care record. Entries can be made into the record at each appointment, resulting in benefits for both the patient and their clinicians because a record of information is available at all appointments. Additionally, patients can note questions they wish to ask at the next appointment. This report also highlighted that each of these factors resulted in time saved for clinicians.

Reducing repetition of investigations

Coffey and Morris (1993) reported that information carried by patients could result in cost savings through less repetition of unnecessary investigations. Though this related mainly to maternity patients, lack of current reports can also result in duplication of investigations for cancer patients.

Improving physical, psychosocial and continuity of care

In 2001, The Northern and Yorkshire regional NHS Modernisation Program reported on the improvements in communication between health professionals and the patient and their family following the implementation of a patient held record. The program report cited three aims of the introduction of the record were. These were:

1. To facilitate open, honest and high quality communication
2. To enable the provision of the highest level of physical and psychological support for the patient
3. To support the multidisciplinary process.

The outcomes of the introduction of the patient held record in this program were that 95% of patients and 98% of health care practitioners recommended its ongoing use. The personal care record resulted in improved communication, improved continuity of care, a greater degree of openness and honesty in health care professionals' approaches to patients and their families and greater consistency in the advice given to patients regarding treatment and care.

MacStravic (1988) also described the increase in patient satisfaction with the use of consumer orientated records.

The negative impacts

Few negative impacts were reported in the literature, but it was noted that patient held records can not replace effective communication between health professionals and patients and their families (Williams et al, 2001). These authors also noted that many clinicians were concerned about the additional documentation.

Important principles for consideration

Many of the papers discussed the principles for development of a personal care record and these included (NHS, 2003):

- Who is to benefit?
- Is the record acceptable to patients?
- Is the record adequate for the stated purpose?
- How is medical correctness ensured?
- What kind of language is to be used?
- Is the record to be optional?
- How will the record be constructed in terms of size, durability & portability
- What will the content of the record include?

Contents of the record

In the literature examined, the contents of the record varied and contained a range of the following:

- Personal, family and support information
- A proposed care plan
- Details of diagnosis, surgery, pathology and referral for adjuvant therapy
- Pathology report
- Medical oncology details
- Radiation oncology details
- Progress notes
- Details about lymphoedema
- Consent to be contacted
- The patient's personal notes
- Appointment summary & questions the patient wishes to ask
- Instructions for the patient and health professionals
- A record of medications
- Side effects of medication
- Places to access information
- The clinical pathway

(NHS, 2003)

Personal Care Record Project Objectives

The objectives of the project were to develop a personal care record that will:

1. Provide a concise, written, individual record to assist the woman and her family in understanding her diagnosis and breast cancer management
2. Provide the woman with information that can be discussed with different members of the multidisciplinary team to assist her to make informed decisions regarding her ongoing individual care
3. Assist communication between the woman and the multidisciplinary team throughout her breast cancer management, particularly when it is undertaken at different locations both within and between the acute and primary care settings.

Development of the Personal Care Record

In August 2000, the North Eastern Metropolitan BSEP established a personal care record working group. Its members were representative of the different health professionals involved in the care of women with breast cancer, and of St. Vincent's Health, Austin Health, Peter MacCallum Cancer Centre, The Northern Hospital and St. Vincent's BreastScreen.

Members of the Consumer Advisory sub-committee of the North Eastern BSEP formed an independent personal care record working group to ensure that consumer input into the development of the resource occurred. Effective management and communication processes were established to ensure content and drafts were reviewed and agreed to by both groups at key stages throughout the project.

Prior to the first meeting, members of both groups received:

- A document summarising key themes obtained from a literature review of patient held records. These themes included a definition of the patient held record, purposes for which they are used, information on possible content and formats, ethical considerations, evaluation methods and past problems with patient held records.
- A table listing all of the printed information received by women with breast cancer from breast clinic, day oncology, chemotherapy, radiotherapy, allied health professionals, palliative care and hospital admission units at St. Vincent's Hospital, Austin and Repatriation Medical Centre and Peter MacCallum Cancer Institute. This was to ensure that the personal care record developed did not duplicate what women already received during their care.

Members of both groups determined that the key elements of the BSEP personal care record would be

1. Accurate information and content

2. Portability, durability and a presentation that would be appealing to women
3. A high level of consumer satisfaction,
4. A high level of health professional satisfaction.

These four elements guided the development of appropriate evaluation strategies.

By August 2001 a draft document was developed. Its content was classified under the following headings: multidisciplinary team; management flow charts; appointments and medications; personal; further information; and pathology reports.

Two graphic design companies were approached to develop a product 'pitch' to be presented to a combined group inclusive of the members of the working group, consumer advisory sub-committee and BSEP staff. Both companies received a brief for the personal care record outlining the purpose, aims, specifications, development timelines, selection criteria and project budget. They presented their 'pitch' inclusive of ideas and 'mock' journals at a meeting on 27th August 2001. Participants rated each product based on its appearance; durability; design features; user friendliness; appropriateness for women with breast cancer; appropriateness for health professionals and overall impression.

The health professionals and consumers differed in choice of product. The consumers wanted something that looked professional and would be taken seriously – not something that looked like a 'pretty diary'. The health professionals expressed surprise at the women's choice and reasoning, as they had all chosen the product that they thought would appeal to women because they saw it as 'feminine and visually appealing'. Following discussion, the consumer preference was chosen for ongoing development. The final product was completed by October 2001. Two hundred personal care records were initially printed at a total cost of \$55 per unit.

At this stage the Barwon South Western BSEP was exploring development of a *Handheld Record* and although extensive consultation had been undertaken, consensus regarding format and content had not been achieved. A major concern of clinicians in that region was that the recording requirements of a *Handheld Record* might increase the workload on clinicians during consultations. When the North Eastern BSEP offered the personal care record for trial in the Barwon region the members of the Regional Reference Groups agreed unanimously. The concern of the clinicians was addressed, as the woman would complete most of the documentation in the BSEP personal care record.

Prior to commencement of the trial in the Barwon region, consultation with local breast care nurses was undertaken and guidelines were developed for the introduction and evaluation of the personal care record.

A Geelong printer was approached to reprint 250 personal care records for the Barwon & South Western region and the total cost of each unit was reduced to just below \$10.

Ethical Considerations

The Human Research Ethics Committee at each of the health services was contacted and details of the project were outlined including aims, objectives and evaluation methodology. Ethics committee approval was not required at either site as the project was viewed as a quality improvement initiative.

Description of the Personal Care Record

The finished personal care record is a diary-sized booklet of around 50 pages with a purple, hard plastic cover. It is designed to fit in a medium to large handbag so that women can carry it with them to appointments. It is divided into the following sections:

- Multidisciplinary team

This lists the health professionals who may constitute a multidisciplinary team in the management of breast cancer. It also has sections for notes and contact details of relevant health professionals that the woman can fill out herself. This section also has information about chemotherapy, hormone therapy and radiotherapy and room for notes about each of these treatments.

- Management flowcharts

Flowcharts for early breast cancer; locally advanced or advanced breast cancer; chemotherapy/hormonal therapy and radiotherapy sit in this section. These flow charts allow the women to better understand where they are in their treatment process and what they can expect.

- Appointments and medications

This section contains pages that can be filled out individually with details of appointments and medications.

- Personal

More space for recording contact details of different health professionals or support people; a space for writing questions and several pages for recording notes are included in this section.

- Further information

This section contains details of breast cancer support organisations; useful resources and definitions of commonly encountered terms are located here. For the purposes of the trial, this section also contained an information and consent form and a sample of

the survey that would be used to evaluate the record and which subsequently provided the information for this report. These latter sections would not be included in future versions of the personal care record.

- Pathology reports

This final section provides a place for women to file copies of their pathology report/s.

Distribution of the Personal Care Records

In the North Eastern Metropolitan BSEP, members of the multidisciplinary team at each participating hospital were approached to assist with the implementation and evaluation of the personal care record. They were asked to offer the personal care record to all patients diagnosed and treated for breast cancer over a six-month period, with a stated preference that patients were offered the personal care record as close to diagnosis as possible. This time frame extended to twelve months at most sites to ensure adequate numbers for evaluation.

Women were required to complete a written consent form prior to accepting the personal care record indicating their understanding that the personal care record was being trialed and evaluated. The team members were asked to complete a Distribution Running Sheet that allowed coding and tracking of women who accepted the personal care record. The team members were also asked to document details of the women who declined the personal care record, stating the reason for decline. However, the reason for declining the offer of the personal care record was not always documented, nor did the documentation reflect the number of women who were not offered the personal care record and the reason for that decision by the health professional. Personal care records were coded to enable tracking of numbers distributed.

In the Barwon region the personal care records were given to women by the breast care nurses as close to diagnosis as possible. Breast care nurses in this region also offered the personal care record to women further along the treatment pathway as it was thought their feedback may add insight into the needs of women from a retrospective viewpoint about information they would like included in a personal care record.

Consumer Survey Methodology

Surveys were mailed to those consumers who received personal care records at time intervals of three months, six months, and 10 months after they first received their records. 253 surveys were mailed to consumers at three months, with 163 (83 from North Eastern and 80 from Barwon) surveys returned. 233 surveys were mailed to consumers at six months, with 115 (66 from North Eastern and 49 from Barwon)

surveys returned, and 124 surveys were mailed to consumers at 10 months, with 43 (35 from North Eastern and 8 from Barwon) surveys returned.

Results were analysed using the Statistical Package for the Social Sciences, version 10 (SPSSwin). Analyses include Cronbach alpha reliability, principal components factor analysis, t-tests, and descriptive statistics. Responses to open-ended questions were used to provide clearer meaning to the statistical findings.

The surveys

The three-month survey consisted of 17 quantitative questions, and two open-ended questions. The quantitative questions concerned the:

- value of the personal care record to users
- frequency of use of the personal care record
- participation of health professionals in the use of the personal care record.

The two open-ended questions asked respondents to comment on how they found the personal care record and how they thought the personal care record could be improved.

The six-month survey consisted of 18 quantitative questions and two open-ended questions. The quantitative questions concerned the;

- ease-of-use of the personal care record
- frequency of use of the personal care record
- time when the personal care record was most frequently used
- participation of health care professionals in the use of the personal care record.

The two open-ended questions were the same as in the three-month survey.

Demographic data was not collected on consumers who participated, nor breast cancer type or stage.

Survey Reliability

The three-month survey was tested for inter-item internal consistency reliability using Cronbach's alpha. A high level of inter-item reliability was evidenced with an alpha of .84. The six-month survey was shown to be even more reliable, with a Cronbach's alpha of .88. Alpha ratings of .70 are generally considered to be reliable. The high reliability of the surveys indicates that participants' responses were accurately measured. The 10-month survey did not contain enough items for a calculation of a Cronbach's alpha, and results from that survey are not a focus of this report.

Internal consistency reliability tests are appropriate for attitudinal surveys, as they are able to establish at one testing if respondents are reading, understanding, and answering the questions in a consistent fashion. Test-retest reliability measures are not appropriate for measuring the reliability of constructs that may change over time, as it is impossible to determine if variations in response are due to a non-reliable instrument, or due to a change in attitudes.

Survey Results

In order to establish the central constructs measured by the three-month survey a principal components factor analysis was performed on quantitative variables, using an oblique rotation. Three clear factors emerged:

- Ease of use
- Use with professionals
- Amount used

The first factor, **ease-of-use**, was measured by:

- question 5 (.816) - "The survey was easy to understand"
- question 7 (.797) - "The different sections of the record were practical"
- question 2 (.791) - "The explanation on how to use the record was clear"
- question 13 (.702) - Overall, "the personal care record is (rating)"
- question 9 (.669) - "The personal section was a useful part of the record".

The second factor, **use with professionals**, was measured by:

- question 11 (.730) - "I see value in health professionals writing in my record"
- question 12 (.668) - "I found it difficult to ask health professionals from the breast unit multidisciplinary team to write in my record."

The third factor, **amount used**, was measured by:

- question 14 (.820) - "I personally used the personal care record"
- question 10 (.795) - "I often took the record to the hospital and/or clinic appointments"
- question 3 (.763) - "The record assisted me in understanding my care"
- question 1 (.763) - "I found my personal care record useful"
- question 4 (.726) - "The record helped me in making decisions about my care."

Differences between sites

The results of the three-month survey showed no differences between the two sites in:

- Consumers impressions of **ease-of-use**
- How much consumers reported using the records.

There were, however, differences between how consumers reported the participation of health-care professionals when filling out the records. On a five-point scale, North Eastern consumers rated health professional involvement with their reports at 3.40, while Barwon consumers rated health professional involvement with their reports at 2.48, $t(122) = 4.65$, $p < .0005$.

When was the record most used?

Consumers were asked at which of the following points in their treatment they found the record to be most useful:

- At diagnosis
- During their hospital stay
- During the first weeks after surgery
- Just before commencing chemotherapy or radiotherapy,
- During chemotherapy or radiotherapy
- After chemotherapy or radiotherapy
- Before or after hormonal treatment.

Consistently, consumers found the personal care record most useful in the period from diagnosis to the conclusion of their chemotherapy / radiation treatments.

One consumer made the following comment:

“After 12 weeks of chemotherapy followed by 6 daily treatments of radiotherapy I did not feel the need to write things on a weekly basis.”

In general, participants found that as their number of appointments decreased, and their understanding of their illness increased, their need for the personal care record decreased after the first few months.

Figure 1 indicates the results of this section of the survey.

Respondents who were already receiving treatment when the personal care record became available often saw the value they would have received if they had had it at diagnosis. The following quotes are representative of comments regarding this:

“I would have found it more useful if the personal care record was available at the time of diagnosis.”

“Had I had it when first diagnosed it would have been handy.”

“Easy to use. Would have been more useful at an earlier stage.”

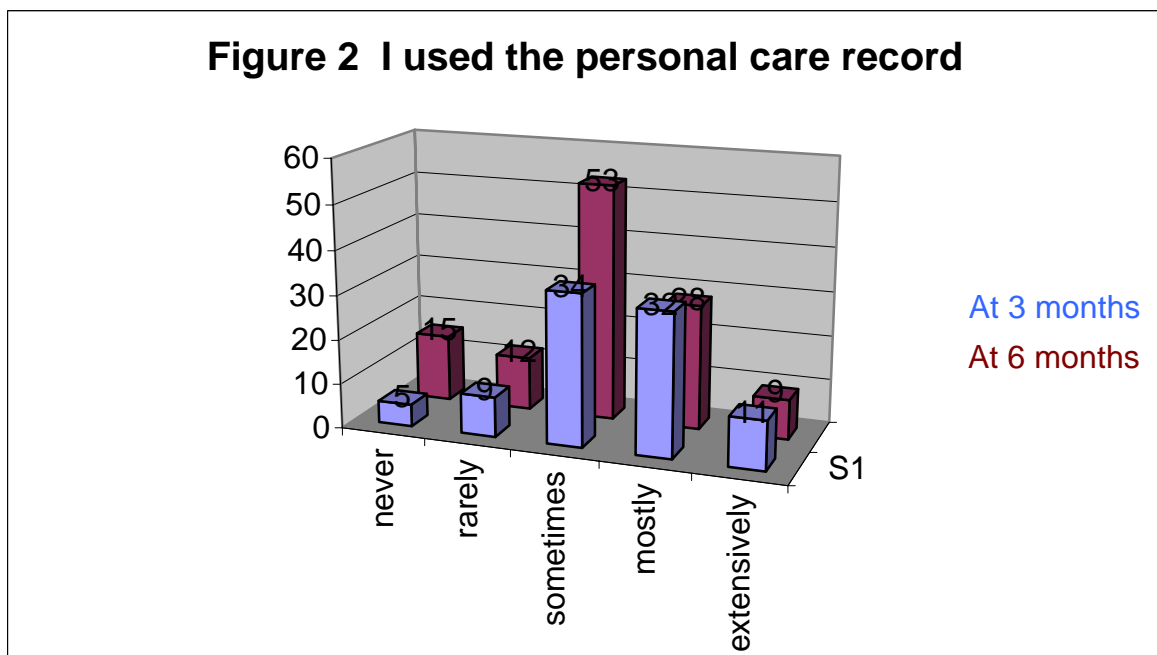
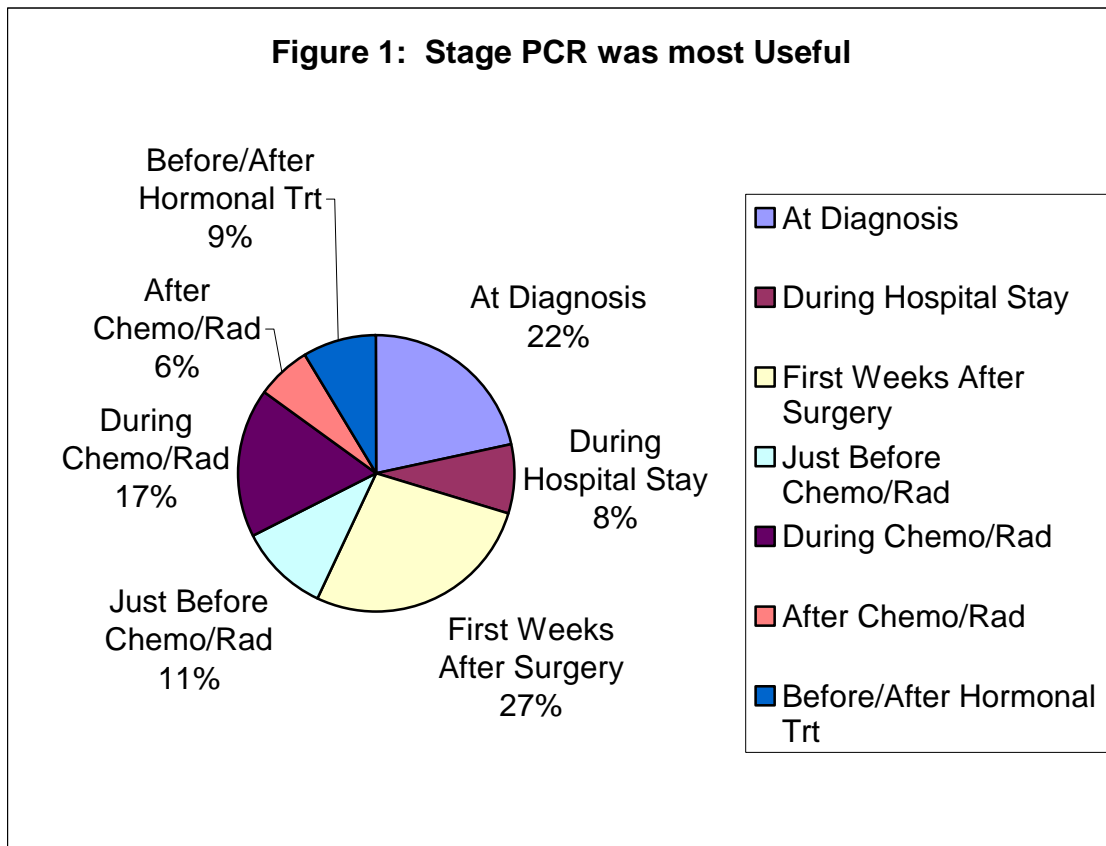
Frequency of use

Consumers were asked to indicate the frequency of their use of the personal care record on a five-point scale from never to extensively. There was a significant difference between respondents' replies from three months to six months in their treatment.

Participants indicated that they used the personal care record more frequently during the first three months (M=3.38) than after the first six months (M=3.09), $t(90) = 3.438$, $p < .001$. At three months only five of the 91 respondents indicated that they never used the personal care record, while at six months, 15 respondents indicated that they were never using the personal care record (Figure 2)

At three months more respondents indicated that they used the personal care record either mostly or extensively as compared to six months. While at six months, more respondents indicated that they either never, rarely or sometimes used the personal

care record compared to those indicating the same frequencies at three months. This question was not asked in the ten-month survey.



The following quotes help illustrate the statistically significant difference between the frequency of use of the personal care record between three and six months:

“My use of the record has decreased, mainly because I haven't needed follow up treatment & my appointments are getting further apart.”

“I don't need it as much now that I have finished my treatments but I use I for recording my appointments.”

“I have become more familiar with terminology and what to expect. Increased rapport with oncologist and staff at day-centre enabled me to have queries answered promptly. As time progressed I used it less.”

“Initially it was used extensively, as the six months proceeded I needed it less often. Less appointments to record.”

Overall attitude to the personal care record

Respondents viewed the personal care record at both three and six months as an excellent resource. Tables 1 and 2 indicate a general positive impression about the personal care record. In particular, respondents found it clear, practical, and easy to understand.

Table 1: Three Month Survey Statements most agreed with:

	Mean	Std Deviation
Question 5 The record was easy to understand	4.31	.56
Question 2 The explanation on how to use the record was clear	4.31	.59
Questions 6 The handbag size of the record was practical	4.31	.80
Question 7 The different sections of the record are practical	4.26	.62
Question 13 Overall the personal health care record is (excellent)	4.19	.76

Table 2: Six Month Survey Statements most agreed with:

	Mean	Std Deviation
Question 5 The print was easy to read	4.39	.67
Question 4 A copy of my pathology results would be helpful	4.34	.90
Question 12 I would recommend this record to other women with breast cancer	4.19	.89
Question 13 Overall, the personal care record is (excellent)	4.15	.88
Question 7 The breast cancer management flowcharts were helpful	4.03	.80

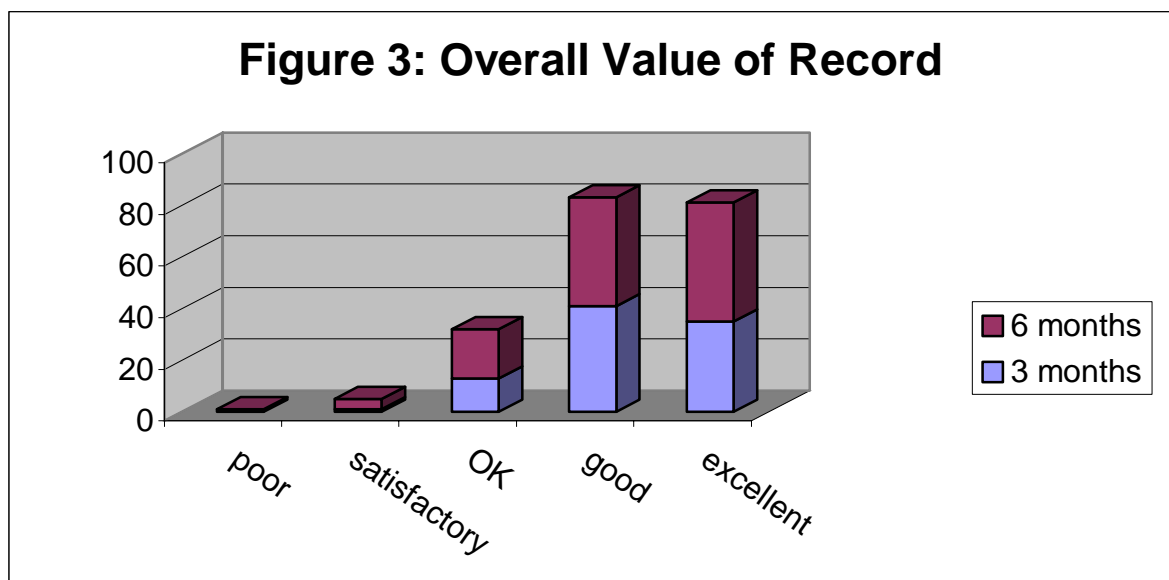
Consumers were also asked to rate the overall value of the personal care record on a five-point scale from poor to excellent. Figure 3 illustrates the responses to this question. Over 75 percent of respondents felt the personal care record was either good or excellent.

One participant made the following comment:

“Thank you so much for putting the PCR together. It has been a great reference material for myself. I do hope that other women have found the usefulness of it.”

Another participant commented:

“It is easy to take with you, all information in one small book, helpful to plan and look forward to a future.”



The following quotes further illustrate impressions consumers had concerning the personal care record:

“Very helpful, I kept checking on details.”

“Very useful as it enabled (me) to keep and maintain notes relating to the treatment in one compact notebook.”

“I found the personal care record most useful as I can keep all my personal information in it and refer to it when I need to.”

“One of my doctors said it was not a very good idea.”

“Didn’t bother (asking health professionals to write in the personal care record), not enough time”.

“I found the personal care record excellent especially when looking up dates for appointments with doctors for x-rays.”

“Great help when I was diagnosed. Breast cancer nurse, surgeon & oncologist told me all I needed to know.”

“I would add a small section for important phone numbers & addresses of family and friends and people you may need to babysit etc. It is very difficult to remember names and numbers after you have been diagnosed and are running to appointments, etc.”

“Make it available to all cancer treatment centres.”

While, many respondents said they would not recommend changing the record, some respondents had the following suggestions for improving the personal care record:

“More spare pages to write on.”

“More room for personal notes. Have pages available to add to book when needed.”

“A calendar would be handy.”

Health Professional Feedback

Between September and December 2003, health professionals working in the acute health settings in the regions covered by the North Eastern BSEP and the Barwon and South Western BSEP were asked to provide feedback on the Personal Care record via a questionnaire.

Forty-six health professionals returned the questionnaires-12 from the Barwon region and 34 from North Eastern. The respondents were representatives of each discipline as listed:

- 6 breast care nurses
- 9 medical oncologists
- 5 oncology nurses
- 1 pathologist
- 1 physiotherapist
- 1 psychologist
- 1 radiation oncology registrar
- 7 radiation oncologists
- 1 radiologist
- 1 regional breast care nurse
- 1 social worker
- 11 surgeons
- 1 trial coordinator

The questionnaire consisted of two open-ended questions seeking information relating to the health professionals' awareness of the personal care record and whether women requested health professional input into their personal care records. In addition, there were four quantitative questions seeking the health professionals' opinion of the value of the PCR regarding:

- Facilitating discussion with the women
- Enhancing womens' understanding of planned management
- And as a general resource for women with breast cancer.

There was also an opportunity to provide general comments and suggest improvements to the personal care record.

Two of the questions in the health-professional questionnaire were identical to those asked of the women. The first related to the helpfulness of the breast cancer management flowcharts and the second related to the perceived benefit of the personal care record to women diagnosed with breast cancer in the future.

Table 1 demonstrates that women rated the flowcharts as more useful than health professionals. In addition, the majority of both health professionals and women thought that women diagnosed in the future could benefit from using a personal care record with 81% of women and 57% of health professionals responding positively to this question (Table 2).

Table 1.

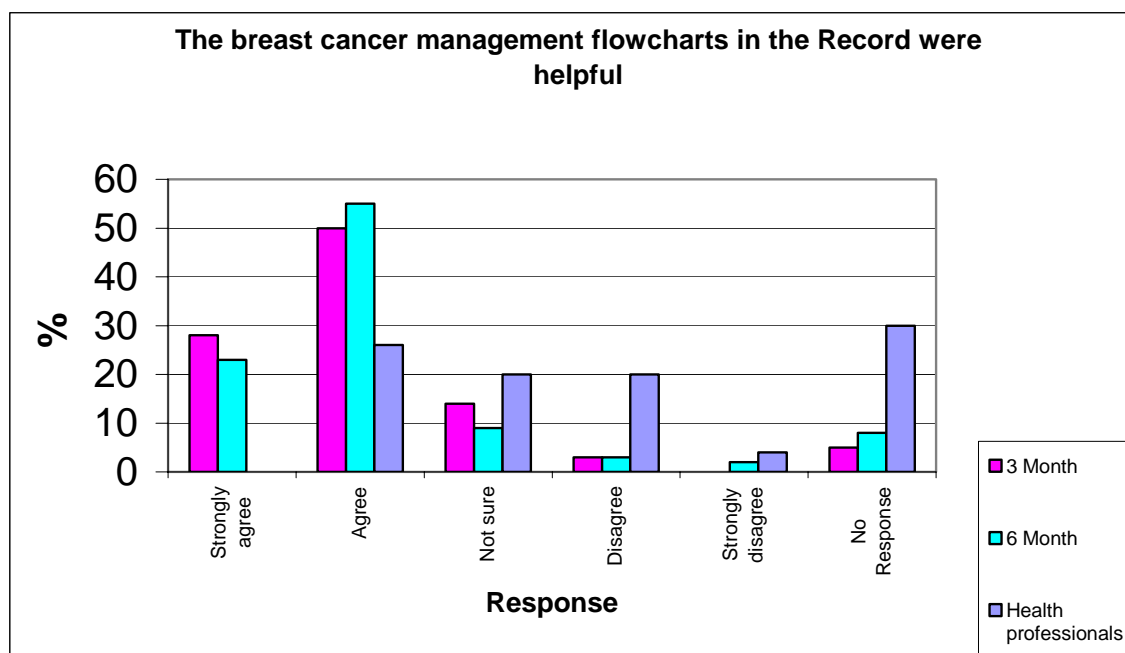
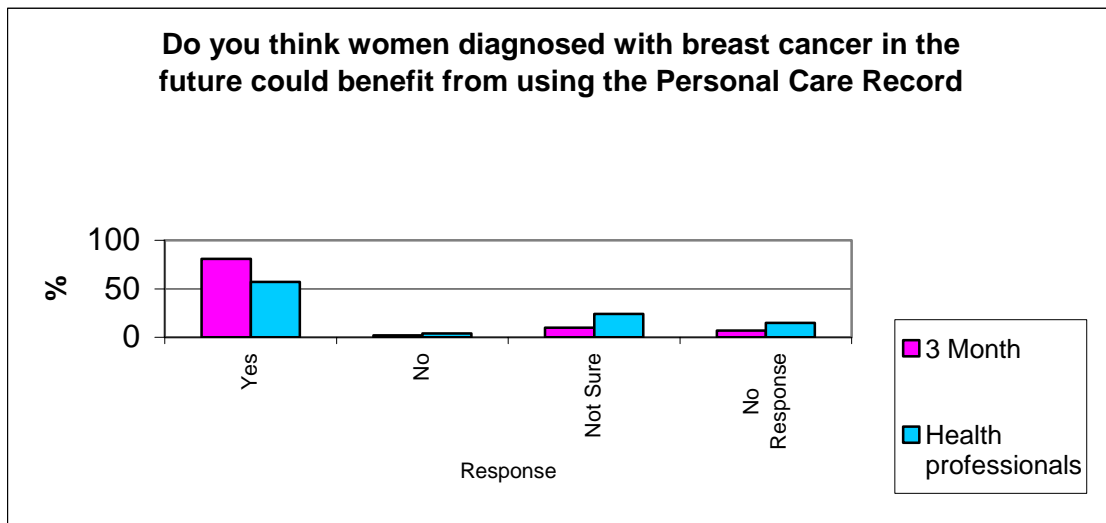


Table 2.



Comments from health professionals varied and are reflected in the following quotes:

“The few people I did see with them seemed to find them useful.”

“Have never seen one therefore cannot comment.”

“In principle a good idea but not evident in consultations.”

“Excellent idea-very useful to have succinct summary of treatments and dates.”

“Give them out! Patients to present them to doctors to write in them.”

“Seems to be useful to some, not all women. Gives them a place to keep things and a guide to the journey.”

“Hopefully this is not information overload at the time of diagnosis.”

“Probably most relevant at time of initial diagnosis and treatment. PCR should be a different colour.”

“The PCR has little impact on my interaction with my patients, but several individual patients I know have found them useful.”

“Women need to be given it on diagnosis and need encouragement to utilize (it). A very useful tool, however, it gets forgotten.”

“I think all patients admitted with a chronic condition, including all cancers, would benefit from a PCR record to assist in confirming or defining treatment or options.”

“More paperwork!”

Discussion, Conclusions & Recommendations

There are a number of clear conclusions that can be drawn from the survey results. Firstly, women appreciated and were pleased with the personal care record. Consistently, they rated the record as excellent with a four-plus rating on a five-point scale.

It was clear that women found the personal care record most useful during the first months of their treatment when they had more appointments, and needed the most new information. There were statistically significant differences between the frequency of use of the personal care record between three and six months.

There were few differences between the two sites included in the trial, North Eastern and Barwon. Analysis of the two statements, "I see value in health professionals writing in my record", and "I found it difficult to ask health professionals from the breast unit multidisciplinary team to write in my record" revealed that North Eastern participants found it easier to use the record with health professionals. Participants from both sites agreed on the two major conclusions above, that the record was very useful, and that it was most useful during the first months of treatment.

Despite the fact that both women and health professionals see the personal care record as a potentially useful tool, comments from women and health professionals indicated that women did not always present them at consultations and health professionals did not always ask for them.

It is acknowledged that the personal care record will not be suitable for use by all women. However, this evaluation does not provide us with information regarding the characteristics of those women who will receive the greatest benefit from the personal care record. We therefore recommend that the personal care record be offered as a resource to all women.

Our results were consistent with some of the findings previously published in the literature. However, we are unable to comment on whether the personal care record had any effect on consumer participation, communication between the women and health professionals and between health professionals, reducing investigations or improving care for patients.

The feedback received indicates that some of the objectives for this project were realised. Consumer feedback demonstrated that the personal care record assisted most women to better understand and make decisions about their care. The majority of consumers also found the personal care record easy to understand and practical in size.

The most notable conclusion that can be drawn from this evaluation is that the personal care record is viewed by those who have used it as very valuable. It is therefore our recommendation that the personal care record, or a similar record, should be made available across the State. Women who are diagnosed with breast

disease find themselves inundated with difficult information and processes at the very time when their foundations of self are threatened. “What can I expect?”, “Where am I in the process?” and “Who can I call?” are real concerns for women. There is evidence from this evaluation that the personal care record may help clarify some of these issues for women. While not every woman will find it useful, the evaluation results indicate a potential benefit for many women of making the personal care record available as close to diagnosis as possible.

The evaluation of this project provides further evidence supporting previous studies into the value of personal care records (patient held records) in the cancer care setting. The process undertaken, content description and findings provide a platform for the development of effective patient held records in the broader cancer field.

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