

INFORMATION PROJECT REPORT

Meeting the information needs of women
with breast cancer
at the time of diagnosis and
treatment completion

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EXECUTIVE SUMMARY

The provision of information to those experiencing breast cancer was identified as a key priority area for improvement by the Breast Disease Redevelopment Strategy (1997). Research evidence indicates that women want and use information resources as a means of coping with the cancer experience as do their partners and families.

A preliminary survey conducted in the consortium revealed considerable variation in clinicians' information giving practices at the time of diagnosis and there were a number of reasons for this. Consultation with consumers revealed that the time of treatment completion is a period when women often experience low levels of support. In addition, oncologists and nurses expressed concern at the limited number of written resources available to offer women at the time of treatment completion.

To address the issues raised, the Inner and Eastern Melbourne BreastCare Consortium proposed a strategy which aimed to develop and trial information packages provided to women at two time points along the disease continuum:

- the time of diagnosis of early breast cancer and
- the time of treatment completion for early breast cancer.

A highly consultative process was undertaken for the development of the packages. In the first stage, an expert group (a multi-disciplinary group of health professionals and a consumer) reviewed a large number of written resources sourced from local, state, national and international organisations. The resources were selected using the following criteria:

- information reinforces clinicians' advice
- assists women to achieve optimum health
- encourages women to utilise support services
- addresses issues such as sexuality and fear of recurrence

In stage 2, the shortlist of resources selected by the expert group was then reviewed by 2 groups of consumers who rated the resources according to how essential they were for women who had just been diagnosed or who were completing treatment for early breast cancer. Results from the 2 consumer groups were aggregated, resulting in a selection of resources for inclusion in each of the information packages. Final package contents included a mix of clinical, psychosocial and practical information.

Nine health care providers (comprising surgeons and breast care nurses) distributed the appropriate package to women either at the time of diagnosis or around the time of completing radiotherapy treatment. At the end of the trial period, 12 women had received the diagnosis package and 31 the treatment completion package.

To evaluate the packages, 28 women participated in a telephone interview conducted 6 to 8 weeks after receipt of the package. Sixty-five percent of those interviewed either read all or selected resources thoroughly. The remaining women (35%) read parts of all or selected resources. Thirty-six percent of women had a partner, other family member or friend who also read the package.

The women's response to the package was overwhelmingly positive and results reflect that women are able to select resources that are relevant and of interest to them. Many women who received the treatment completion package indicated that the package contained resources that they would have preferred to have received earlier in their treatment.

Health care providers also responded positively to the package indicating that it was comprehensive and helped to meet the information needs of their patients.

BACKGROUND

The relationship between information provision and its possible effect on the post treatment outcomes of oncology patients has been the focus of many studies in the past decade. Research findings suggest that lack of information can increase a patient's anxiety, uncertainty and dissatisfaction with services (Fallowfield et al 1995). Further evidence also indicates that doctors generally underestimate not only the amount but also the sort of information that patients require (Fallowfield et al 1995). In addition to this, a study by Rodriguez-Marin and colleagues (1996) showed that regardless of the content of information, the most important choice for doctors was whether to give information or not. Research by Fallowfield and colleagues (1995) revealed that most patients expressed a desire for as much information as possible, be it good or bad.

Several studies have shown that a patient's preference for acquiring information is related to the coping strategies they utilise and their attitude to managing their cancer (Luker et al, 1996 and Rees et al, 1998, Leydon et al 2000). Luker and colleagues (1996) argue that the fear and apprehension patients' experience prevents them from requesting specific information from health care providers. Spouses and family members also require information similar to that of the patient, as this helps them to cope with the breast cancer experience (Rees et al, 1998).

Leydon and colleagues (2000) discuss the challenge of finding ways to provide information that is appropriate for patients who may benefit from knowing something about their illness and its treatment but may not wish to know everything about it at all times. Luker et al (1996) declare that in order to enable effective patient participation, health carers need to provide relevant and appropriate information. A study on information packages for cancer patients by Whelan and colleagues (1998) confirms that written information is an effective means of improving transfer of information from health care providers to patients.

The "Psychosocial Clinical Practice Guidelines: providing information, support and counselling for women with breast cancer" (NHMRC, 2000) provide research evidence indicating that the psychological impact of breast cancer is significant and that women with cancer repeatedly report a desire to be well informed. For example, Devine and Westlake (1995) found that adequate information provision to women with breast cancer is related to increased psychological wellbeing. The guidelines assert that women feel capable of comprehending and utilising information at the time of diagnosis and that access to this information is of major importance to them.

Research exploring the longitudinal emotional impact of breast cancer has raised awareness of the woman's need for ongoing psychosocial care. The Psychosocial Clinical Practice Guidelines strongly recommend that information should be available for women at both the time of diagnosis and the time of treatment completion.

PROJECT AIMS

The Breast Services Enhancement Program (BSEP) aims to improve the quality, accessibility and coordination of services delivered to women with breast cancer. Consultation with consumers in the development phase of the Inner and Eastern Melbourne BreastCare Consortium's Information and Communication strategy, provided details of women's experiences of information provision during their breast cancer journey. It became evident that women's access to information was not equitable, particularly at the time of diagnosis, and there were a variety of reasons for this. In addition to this, treatment completion was a time when oncologists expressed concern about having limited resources to offer women and women reported it as a time of high support need.

In response to this need, packages of information were researched and developed for women at two of the 'critical' points in the disease continuum: the time of diagnosis of early breast cancer and the time of treatment completion.

The project's aims were to:

- A. Improve women's access to information
- B. Improve the information giving practices of health care providers
- C. Provide women with information that:
 - assisted their understanding of their condition and its clinical management, and
 - facilitated their access to support services available

METHODOLOGY

An advisory group was formed to guide the project's development and methodology. This group comprised a consumer (with a background as a librarian), a cancer expert (radiation oncologist), an experienced breast care nurse (BCN), a nurse manager from a major metropolitan breast unit, a research psychologist (with experience in communication issues in oncology), a publications manager (from The Cancer Council Victoria) and the BSEP's Manager and Project Officer. Each member of the group had a good understanding of the issues women with breast cancer faced along the disease continuum.

This project was carried out in five stages:

1. Health care provider survey
2. Project development
3. Resource selection
4. Information package distribution
5. Phone evaluation of project participants

1. HEALTH CARE PROVIDER SURVEY

At the start of this project, a preliminary survey was conducted within the consortium. The survey explored the provision of written resources by health care providers. It identified that information provision throughout the disease continuum varied, particularly at the time of diagnosis and treatment completion. Interestingly, the survey found that the information needs of women receiving adjuvant therapy (chemotherapy and radiotherapy), were adequately provided for by health care providers. A plethora of general oncology and treatment specific written resources were offered to women at this point in the disease continuum.

2. PROJECT DEVELOPMENT

The survey results together with the evidence base were utilised in the development of several proposals for consideration by the advisory group. The proposal selected by the group, involved the development of packages containing information relevant to two 'critical' time points in the disease continuum: the time of diagnosis of early breast cancer and the time of treatment completion.

The aim was to develop packages containing written resources (booklets, pamphlets, etc) which would provide women with information particularly targeted to their needs at these 2 key points in the continuum.

Having determined the scope of the project, it was decided to utilise information resources already available rather than to produce new resources. An extensive range of breast cancer literature had been produced by Victorian, national and international cancer organisations. The Internet, an increasingly popular source of information, also offered an immense selection of breast cancer information produced by commercial, educational, government and medical organisations.

To enhance the validity and appropriateness of the resources selected, both experts in the field and consumers were involved in the selection process.

3. RESOURCE SELECTION PROCESS

SELECTION CRITERIA

The criteria for resource selection was based on the aims of the project and recommendations made in the Psychosocial Clinical Practice Guidelines (NHMRC, 2000). The content of each package needed to reflect key issues occurring at each of the critical points identified. The selection criteria for each package, endorsed by the advisory group, are listed below.

Diagnosis package:

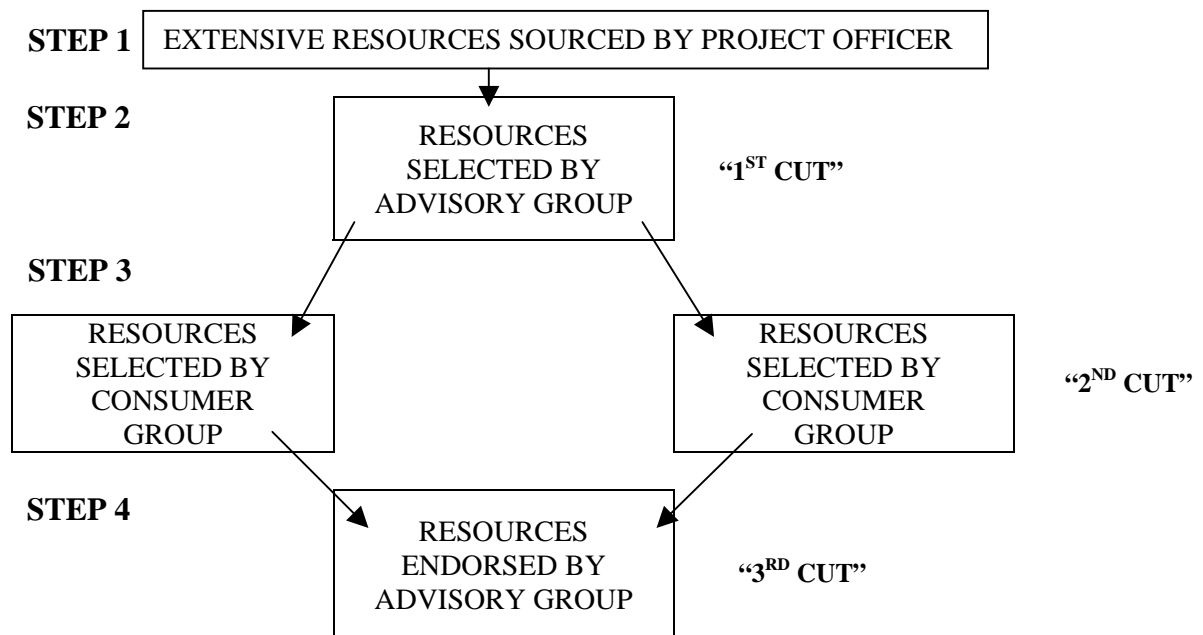
- Information that assists women to understand the diagnosis and its implications
- Information that assists women in treatment choice (including information about trial surgical/ oncology procedures)
- Information regarding support available to women, their family and carers

Treatment completion package:

- Information that assists women to achieve optimum quality of life
- Information about good health practices
- Information that encourages women to continue accessing support services
- Information that reinforces clinician advice regarding routine follow up care
- Information that assists women to address issues such as sexuality, fear of recurrence and family needs

The process for determining which resources would be included in each package entailed four steps: (see *Diagram 1*)

Diagram 1



STEP 1. Selection by the Project Officer

The initial extensive set of resources (38 in total) were selected by the Project Officer and were sourced from a number of Australian Cancer Councils, the National Breast Cancer Centre (NBCC), health care providers, an Australian consumer advocacy group and the Internet.

STEP 2. Selection from a wide range of resources by an expert group

For this “1st cut” the experienced advisory group was supplemented by an oncology social worker renowned for her work in the field of treatment completion issues. The group was instructed to review the resources and rate them according to how essential they were for inclusion in each of the packages. The Project Officer devised a 5 point rating scale for this exercise where 1 = not essential and 5 = absolutely essential. This exercise resulted in a shortlist of resources (30 in total).

(See Appendix A for list of resources)

STEP 3. Selection from the shortlisted resources by two consumer groups

In order to obtain a collective consumer opinion of the shortlisted resources, women from several breast cancer support groups were invited to attend one of two workshops.

The twelve consumers who attended the workshops were requested to rate the selected resources utilising the same rating scale as the advisory group. They were asked to draw from both their own cancer experience and that of other women within their ‘networks’. The outcome of each consumer group’s resource selection was combined and aggregated to obtain a final list of resources (35 in total).

(See Appendix A for list of resources)

STEP 4. Final review and endorsement of resources

The advisory group reviewed and endorsed the resources chosen by the consumers. Where information gaps remained, the advisory group endorsed a further selection of resources made by the Project Officer.

Together, these resources made up the final content of the two packages. The final package content is listed on the following page.

At this point, three Australian cancer funds and two health care providers (a medical oncologist and social worker) were approached for their support in the project and requests were made for the provision of their resources which had been selected for inclusion in the packages.

Forty diagnosis packages and 50 treatment completion packages were then assembled with the relevant contents.

FINAL PACKAGE CONTENT

Resources for women at time of diagnosis

1. All about early breast cancer (B)- (*NBCC*)
2. Life with cancer- the uncertainties, hopes and fears (B)- (*ACCV*)
3. Breast cancer treatment guidelines for patients (I)-(*American Cancer Society*)
4. Cancer trials (I)-(*National Cancer Institute*)
5. Breast Cancer: Common reactions of children and how to help (I)-(*University of Winsconsin- Medical School*)
6. Retail Products & Information (B) -(*ACCV*)
7. If you or someone you know has cancer, a cancer support group could help (P)- (*ACCV*)
8. Living with cancer education program (P)- (*ACCV*)
9. Cancer services in Victoria (B)- (*ACCV*)
10. Understanding emotions (B)-(*Qld. Cancer Fund*)
11. Cancer and complementary therapies (B)-(*WA Cancer Fund*)
12. Surfing the net – a ‘safety guide’ for people living with cancer (P)-(*Carrie Lethborg*)
13. Breast care nurses-supporting people experiencing breast cancer (P)- (*ACCV*)
14. ACCV-How we can help (P)- (*ACCV*)

For women at time of treatment completion

1. Breast Self Examination (P)- (*ACCV*)
2. Retail Products & Information (B)- (*ACCV*)
3. Taking care of your feelings (I)-(*National Cancer Institute*)
4. Continuing to care for your health (I)-(*National Cancer Institute*)
5. Breast cancer and sexuality: Surviving and thriving (I)-(*CancerCare*)
6. Treatment completion (B)-(*written by Carrie Lethborg- oncology social worker*)
7. A patient’s guide: Follow up for breast cancer (I) -(*American Society of Clinical Oncology*)
8. Tamoxifen –(B)-(*written by Medical Oncologist Dr Jacquie Chirgwin*)
9. Reducing my risk of lymphoedema -(*Breast Cancer Action Group*)
10. If you or someone you know has cancer, a cancer support group could help (P)- (*ACCV*)
11. Living with cancer education program (P)- (*ACCV*)
12. Cancer services in Victoria (B)- (*ACCV*)
13. Understanding emotions (B)-(*Qld. Cancer Fund*)
14. Cancer and complementary therapies (B)- (*WA Cancer Fund*)
15. Surfing the net – a ‘safety guide’ for people living with cancer (P)-(*Carrie Lethborg*)
16. Breast care nurses-supporting people experiencing breast cancer (P)- (*ACCV*)
17. ACCV-How we can help (P)- (*ACCV*)
18. Making decisions about Hormone Replacement Therapy (P)-(*ACCV*)
19. Exercises for Recovery (P)- (*Qld. Cancer Fund*)

(B)=booklet (P)=pamphlet (I)=Internet source

4. DISTRIBUTION

In order to achieve sufficient sample numbers, packages were distributed to a wide number of health care providers comprising:

- a) a group of surgeons (4) who consulted public patients from their private rooms and who had been identified (through the survey) as providing few resources to women diagnosed in their consulting rooms
- b) Breast Care Nurses (BCN's) in public and private hospitals who had contact with women around the time of diagnosis or treatment completion.

The trial was conducted over a three month period from February to April 2001. Health care providers were asked to offer the relevant package to newly diagnosed women or to women who were about to or had already completed treatment for early breast cancer. A one-page guide accompanied each package explaining to the recipients that the content of the package was of a general nature and that questions regarding a patient's own diagnosis or treatment should be addressed to their treatment team or treating clinicians.

Health care providers were encouraged to review the resources included in the package, in order to address any questions related to its content brought to them by the woman or family. In addition to this, health care providers were asked to refrain from removing any resources from the package. They were however, welcome to provide additional resources as deemed necessary (it was requested that health care providers indicate to the Project Officer where this had been the case and to name the additional resource[s]).

Consent to participate in a follow-up phone survey was sought from all of the women who received a package by the health care providers.

5. SURVEY INSTRUMENT

Recipients of the package who consented, were interviewed using a preset questionnaire (see Appendix B). All interviews were conducted via phone by the Project Officer and took 10- 20 minutes to complete. Women were asked a series of questions about the package in order to determine:

- how they obtained it (who gave it to them and under what circumstances)
- how timely it was (women's satisfaction with the point in time in which they received the package) and
- how valuable it was (suitability and usefulness of resources contained in the package and resources read).

Inquiries were also made as to whether the package contents were read by others- partners, family or friends.

RESULTS

Provision & timing of the package

Of the eighty-four packages distributed to surgeons and BCN's, 43 were provided to women with breast cancer at completion of the trial period. The Project Officer was provided with the contact details of 33 women who had consented to an interview and of these, 28 women (65%) participated in a telephone evaluation of the package received.

Of the 28 women interviewed, 5 (18%) received the diagnosis package and 23 (82%) received the treatment completion package. Only one package was given out as the result of a specific request for information. The others were distributed by health care providers in response to their participation in the trial. Breast care nurses provided the package to a total of twenty-five women. Two women received the package directly from a surgeon and another from a surgeon's secretary (upon the surgeon's request).

Of the 5 women who received the diagnosis package, 2 (40%) received it prior to surgery and 3 received it post surgery. Of these three, two women would have preferred it be offered at a later stage stating that it was a difficult time for them and they still had not come to terms with the diagnosis.

Of the 23 women receiving the treatment completion package, 15 (65%) received it upon or following completion of radiotherapy treatment, and 8 (35%) received it prior to completion of radiotherapy treatment. All women who received the treatment completion package were offered it by a BCN and radiotherapy was their final mode of treatment. Ten women (43%) were satisfied with the timing of the package and the remaining were either not satisfied or unsure if they received it at an appropriate time. Eleven women (48%) would have preferred to receive the treatment completion package much sooner than when it was provided. Levels of satisfaction with the timing of the receipt of the package did not influence women's satisfaction with the package itself. Several women suggested that it be given at the start of radiotherapy treatment (as long as it was the final mode of adjuvant therapy).

Expectations of the package

When asked about their expectation of the package's content, 12 women (43%) expected it to contain information about their cancer, its treatment and support available. Six women (21%) expected it to contain either general cancer information or information that was only relevant to them or information about ongoing care. The remaining 10 women (36%) stated that they were unsure of what to expect. These varied expectations may have been influenced by the way in which the package was offered and presented to them by the health care provider. It is difficult to say whether women's expectations were met or exceeded.

Utilisation

Six of the 28 women (21%) said that they had thoroughly read all the resources in the package, while 12 women (42%) had read some resources thoroughly but not others (this was because certain resources were not relevant to their individual situation). Three women (11%) read some parts of all books, while 6 women (21%) only skimmed through

the information contained in the package. One woman (3%) who received the treatment completion package had not read any of the information as she did not have the time available- she had however kept the package and intended to read it some time in the future.

In total, 10 of the 28 women (35%) acknowledged that family and/or carers had also looked at some or all of the resources. Husbands were the most likely to read the resources followed by friends, mothers and lastly children.

Only two women (7%) in the total sample indicated that there was at least one resource in the package that they found confronting. These women had both received the diagnosis package.

All women indicated that there was sufficient information to guide them to other sources of information if they wished to look further.

Omissions & general comments from consumers

One woman felt the diagnosis package lacked certain information and this related to homeopathic remedies. General comments made by the women receiving the diagnosis package included:

“Books allay fears”

“The more knowledge you have, the better off you are”

“You know what you’re talking about” (when asking doctors questions)

“Pleased to have received it”

“I hadn’t come to terms with it (the diagnosis), but friends got a lot out of it (the package)”

Women who received the treatment completion package indicated that there were several areas of information lacking. These are listed below:

- positive/ survivor stories of how people managed to get through each stage of the cancer journey
- information relevant to younger women who had concerns about taking the contraceptive pill, fertility issues and control of menopausal symptoms
- nutrition information
- specific information on wound care and where to buy wound care products
- information on specific local services available (such as exercise programs)
- information regarding the ongoing side effects of treatment
- greater information on dealing with uncertainty or the fear of recurrence
- information on breast reconstruction

In general, the majority of women felt that the information package was comprehensive and it was ideal to have available or ‘at hand’ so that they could refer to it when needed. A small proportion of women (20%) had previously received some of the resources included in the package during their treatment from BCN’s, other nurses or doctors.

Few women however thought that this was repetitive and in fact most felt that it served to reinforce the information given to them.

Other comments made by women who received the packages include:

“Package was really fantastic, if you have it at the right time you could go in the right direction”

“Package was reassuring to know that you could look something up and know that you’re normal”

See Appendix C for results represented in table format.

Response from health care providers

Preliminary survey

The initial survey conducted for this project was carried out to determine the type and number of resources health care providers were giving to women diagnosed with breast cancer. Through this survey, it became evident that there was a strong belief amongst surgeons (5 in total sample) that at the time of diagnosis, women had difficulty absorbing a great deal of information. For this reason, they offered newly diagnosed women a ‘minimum’ of resources- usually one general breast cancer booklet outlining treatment options. Several surgeons indicated that this was all that was necessary prior to surgery and that other resources would be provided as required by other clinicians and nurses.

Breast care nurses and other nurses indicated that at the time of diagnosis it was common practice to offer women a range of resources. Some BCN’s had a select group of resources that they provided to all women at diagnosis.

The majority of BCN’s and oncologists stated that they either had a limited number or no resources to offer women at the time of treatment completion.

Two health care providers (one a surgeon, the other a BCN- both working in the same unit) declined to participate in the trial on the basis that they believed the packages contained too much information and would cause undue anxiety to their patients.

Post trial survey

Approximately half of the health care providers (54%) who participated in the trial felt that the package was useful in providing a large range of information in various printed formats (i.e. booklets, brochures, information sheets) to women with breast cancer.

One surgeon was keen to offer all newly diagnosed women the package (regardless of whether they were managed in the public or private system or whether access to BCN services existed). Another surgeon however, indicated that he preferred to continue assessing women according to their expressed information needs and offer the information package or select resources as he saw appropriate.

The response from BCN's was exceptionally positive. Breast care nurses felt that the range of resources provided in the package was far greater than they were generally able to access in the limited time they had available to source breast cancer related information.

Interestingly, no health care provider reported adding resources to the package they offered to women.

DISCUSSION

The results of this study indicate that the need for information can vary, regardless of which point along the disease continuum women are at. When provided with a comprehensive information package, women reported that they were able to make their own decisions about what information they read and when.

Of the women who were interviewed, only 2 were offered the package by a surgeon. Despite their willingness to participate in the trial, it appears that surgeons were still selective about who they gave the package to and left it up to the BCN to provide women with information at a later stage.

It may be possible that some of the women were diagnosed through BreastScreen and therefore had received a package of information at that time. Surgeons may have felt that the BreastScreen information package catered for the women's information needs.

More than a third of the women were unsure of what to expect in the package and for the remaining women expectations concurred with the actual content of the package. Although less than half the sample were satisfied with the timing of the package, more than two thirds of women read all or select resources thoroughly. There appears to be no correlation between women's satisfaction with the timing of the package's provision and with the amount of the information they read.

It is acknowledged that the time of diagnosis and pre-surgery is often an overwhelming period for women and many would argue that it is inappropriate to overload women with information that they may have difficulty comprehending or information that may cause undue anxiety. Although the number of women receiving the diagnosis package is small, evaluation showed that 2 of the 3 women who received the package post surgery would have preferred it at a later stage. These women indicated that it was a difficult time for them and they still had not come to terms with the diagnosis.

All the women receiving the diagnosis package gave it to their partner, a family member or friends to read. Twenty-two percent of women had given the treatment completion package to another person to read. Several women indicated that as they reached the completion of their treatment, they felt it unnecessary to further 'burden' their partners or families with even more information about breast cancer.

All of the women interviewed stated that there was sufficient information in the package to guide them to other sources of information and support if they wished for more. The

survey instrument however did not elicit which, if any, services women accessed through the information provided in the package.

Limitations of project

Despite enlisting several health care providers from across the consortium to participate in the trial, the overall sample size remained small, particularly the number of women who received the diagnosis package. This may have been due to the low volume of breast cancer patients managed by the participating surgeons during the trial period. Although 12 women in total received the diagnosis package, 7 were not interviewed due to the fact that they had not consented or were unable to be contacted. This further limits the assumptions that could be made about the information giving practices of surgeons.

Although it was evident that during the trial period health care providers' information giving practices improved slightly, it is unclear whether it is possible to sustain the change. It is also unclear which factors would facilitate the sustainable change.

A number of questions have arisen from the results of the project. These include:

- Does the prepared package eliminate the effort of collating resources?
- Is there a need to review clinicians' practices through a follow up survey?
- Did the information packages satisfy women's needs for written information?
- What of the partners and families? Could they have been surveyed for their response to the package?

Indications for the future

In the planning phase of this project, sustainability issues were identified. If the project proved successful, it was suggested that a consumer organisation might have the ability to maintain and review the package content on a regular basis. At the time of completion of this project, a consumer run information resource centre was to be established with the support of BreastCare Victoria. Such an organisation may have the capacity to review resources, collate and distribute packages to health care providers and directly to women.

The consultation process implemented for the selection of resources proved to be an effective one and is an example of a collaborative process between consumers and health care providers. Such a process would serve as an ideal example for breast services wishing to improve the information giving practices.

CONCLUSION

The current information giving practices of health care providers varies greatly, with no standards or recommendations on content or timing of information provision. Research evidence supports the notion that women desire information throughout the disease continuum, from diagnosis up to and including treatment completion.

Although it is impossible to meet all individual needs with one package, the project demonstrated that when provided with a comprehensive package of information, women are able to self-select the type and amount of information they require. Although satisfaction with the timing of the package's receipt varied, it did not appear to influence women's utilisation of and satisfaction with the package's content.

Health care providers, particularly BCN's, were pleased with the package's ability to meet a range of information needs. The treatment completion was received positively by both health care providers and women with breast cancer, as information related to the 'end of treatment' phase is generally not easily accessed.

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APPENDIX A

PACKAGE CONTENT FOR SELECTION BY EXPERT GROUP

Resources for women at time of diagnosis

1. A consumer's guide: early breast cancer (B)- (*NBCC*)
2. All about early breast cancer (B)- (*NBCC*)
3. Breast cancer: a guide for women (B)- (*ACCV*)
4. Understanding breast cancer (B)- (*Qld. Cancer Fund*)
5. Coping with breast cancer (B)- (*Qld. Cancer Fund*)
6. Life with cancer (B)- (*ACCV*)
7. Breast cancer treatment guidelines for patients (I)- (*American Cancer Society*)
http://www.nccn.org/patient_guidelines/breast_cancer/breast/1_introduction.htm
8. The cancer word book (B)- (*ACCV*)
9. Questions you might like to ask your doctor (P)- (*WA Cancer Fund*)
10. Choosing a surgeon: what's important to you? (P)- (*BreastScreen Victoria*)
11. "Doctor, can we talk?" (I)- (*CancerCare*)
<http://www.cancercare.org/patients/talking.htm>
12. Clinical trials (B)- (*ACCV*)
13. Cancer trials (I)- (*National Cancer Institute*)
<http://cancertrials.nci.nih.gov/understanding/basics/index.html>
14. Treatment options (I)- (*National Cancer Institute*)
http://rex.nci.nih.gov/PATIENTS/aboutbc/treatment_options.html
15. Cancer Facts (8.8) Q & A About finding Cancer Support Groups (I)- (*National Cancer Institute*)
http://rex.nci.nih.gov/INFO_CANCER/Cancer_facts/Section8/FS8_8.html
16. Breast Cancer: Common reactions of children and how to help (I) – (*University of Wisconsin Medical School*)
<http://www2.medsch.wisc.edu/childrenshosp/childrens.html>

(B)=booklet (P)=pamphlet (I)=Internet source

Resources for women at time of treatment completion

1. Breast Self Examination (P)- (*ACCV*)
2. Retail Products & Information (B)- (*ACCV*)
3. Taking care of your feelings (I)- (*National Cancer Institute*)
http://rex.nci.nih.gov/NCI_Pub_Interface/Facing_Forward/factake.html
4. Emotional health (I)- (*National Cancer Institute*)
http://rex.nci.nih.gov/PATIENTS/aboutbc/emotional_health.html
5. Continuing to care for your health (I)- (*National Cancer Institute*)
http://rex.nci.nih.gov/NCI_Pub_Interface/Facing_Forward/facconti.html
6. Breast cancer and sexuality: Surviving and thriving (I)- (*CancerCare*)
<http://www.cancercares.org/campaigns/breast1/htm>
7. A patient's guide: Follow up for breast cancer (I)- (*American Society of Clinical Oncology*)
http://www.asco.org/people/rs/html/m_patguidebr.htm
8. Hormone replacement therapy for breast cancer survivors (I)- (*Toronto- Sunnybrook Regional Cancer Centre*)
<http://www.tsccc.on.ca/obciep/hrt.htm>
9. Tamoxifen – your questions answered (P)- (*WA Cancer Fund*)
10. Tamoxifen- information sheet (P)- (*Qld. Cancer Fund*)
11. Earning a living (I) - (*National Cancer Institute*)
http://rex.nci.nih.gov/NCI-Pub_Interface/Facing_Forward/facearn.html

(B)=booklet (P)=pamphlet (I)=Internet source

Resources for both packages

1. Breast cancer support service (P)- (*ACCV*)
2. Living with cancer education program (P)- (*ACCV*)
3. Cancer services in Victoria (B)- (*ACCV*)
4. Understanding emotions (B)- (*Qld. Cancer Fund*)
5. A guide for the partners of women with breast cancer: how to help (B)- (*Qld. Cancer Fund*)
6. Eating well (B)- (*ACCV*)
7. How can I relax? (B)- (*ACCV*)
8. Cancer and complementary therapies (B)- (*WA Cancer Fund*)
9. Choosing alternative therapies (P)- (*WA Cancer Fund*)
10. Q & A About Complementary & Alternative Medicine in Cancer Treatment (I)- (*National Cancer Institute*)
<http://cancernet.nci.nih.gov/>
11. Complementary & Alternative Methods (I)- (*American Cancer Society*)
http://www.cancer.org/alt_therapy/index.html

(B)=booklet (P)=pamphlet (I)=Internet source

SHORTLISTED PACKAGE CONTENT FOR SELECTION BY CONSUMER GROUPS

Resources for women at time of diagnosis

1. All about early breast cancer (B)- (*NBCC*)
2. Coping with breast cancer (B)- (*Qld. Cancer Fund*)
3. Life with cancer-the uncertainties, hopes and fears (B)- (*ACCV*)
4. Breast cancer treatment guidelines for patients (I)- (*American Cancer Society*)
http://www.nccn.org/patient_guidelines/breast_cancer/breast/1_introduction.htm
5. Choosing a surgeon: what's important to you? (P)- (*BreastScreen Victoria*)
6. "Doctor, can we talk?" (I)- (*CancerCare*)
<http://www.cancercare.org/patients/talking.htm>
7. Cancer trials (I)- (*American Cancer Society*)
<http://cancertrials.nci.nih.gov/understanding/basics/index.html>
8. Breast Cancer: Common reactions of children and how to help (I)- (*University of Wisconsin Medical School*)
<http://www2.medsch.wisc.edu/childrenshosp/childrens.html>
9. What will I tell the children? (P)- (*ACCV*)

For women at time of treatment completion

1. Breast Self Examination (P)- (*ACCV*)
2. Retail Products & Information (B)- (*ACCV*)
3. Taking care of your feelings (I)- (*National Cancer Institute*)
http://rex.nci.nih.gov/NCI_Pub_Interface/Facing_Forward/factake.html
4. Emotional health (I)- (*National Cancer Institute*)
http://rex.nci.nih.gov/PATIENTS/aboutbc/emotional_health.html
5. Continuing to care for your health (I)- (*National Cancer Institute*)
http://rex.nci.nih.gov/NCI_Pub_Interface/Facing_Forward/faconti.html
6. Breast cancer and sexuality: Surviving and thriving (I)- (*CancerCare*)
<http://www.cancercareinc.org/campaigns/breast1.htm>
7. Treatment completion (B)- (*written by Carrie Lethborg-Social Worker*)
8. A patient's guide: Follow up for breast cancer (I)- (*American Society of Clinical Oncology*)

http://www.asco.org/people/rs/html/m_patguidebr.htm

9. Tamoxifen – your questions answered (P)- (*WA Cancer Fund*)
10. Tamoxifen (P)- (*Qld. Cancer Fund*)
11. Reducing my risk of lymphoedema (P)- (*Breast Cancer Action Group*)

Resources for both packages

1. If you or someone you know has cancer, a cancer support group could help (P)- (*ACCV*)
2. Living with cancer education program (P)- (*ACCV*)
3. Cancer services in Victoria (B)- (*ACCV*)
4. Understanding emotions (B)- (*Qld. Cancer Fund*)
5. A guide for the partners of women with breast cancer: how to help (B)- (*Qld. Cancer Fund*)
6. Cancer and complementary therapies (B)- (*WA Cancer Fund*)
7. Choosing alternative therapies (P)- (*WA Cancer Fund*)
8. Surfing the net – a ‘safety guide’ for people living with cancer (P)- (*written by Carrie Lethborg-Social Worker*)
9. Breast care nurses-supporting people experiencing breast cancer (P)- (*ACCV*)
10. How we can help (P)- (*ACCV*)

(B)=booklet (P)=pamphlet (I)=Internet source

FINAL PACKAGE CONTENT

Resources for women at time of diagnosis

1. All about early breast cancer (B)- (*NBCC*)
2. Life with cancer- the uncertainties, hopes and fears (B)- (*ACCV*)
3. Breast cancer treatment guidelines for patients (I)-(*American Cancer Society*)
4. Cancer trials (I)-(*National Cancer Institute*)
5. Breast Cancer: Common reactions of children and how to help (I)-(*University of Wisconsin-Medical School*)
6. Retail Products & Information (B) -(*ACCV*)
7. If you or someone you know has cancer, a cancer support group could help (P)- (*ACCV*)
8. Living with cancer education program (P)- (*ACCV*)
9. Cancer services in Victoria (B)- (*ACCV*)
10. Understanding emotions (B)-(*Qld. Cancer Fund*)
11. Cancer and complementary therapies (B)-(*WA Cancer Fund*)
12. Surfing the net – a ‘safety guide’ for people living with cancer (P)-(*Carrie Lethborg*)
13. Breast care nurses-supporting people experiencing breast cancer (P)- (*ACCV*)
14. ACCV-How we can help (P)- (*ACCV*)

For women at time of treatment completion

3. Breast Self Examination (P)- (*ACCV*)
4. Retail Products & Information (B)- (*ACCV*)
3. Taking care of your feelings (I)-(*National Cancer Institute*)
4. Continuing to care for your health (I)-(*National Cancer Institute*)
5. Breast cancer and sexuality: Surviving and thriving (I)-(*CancerCare*)
6. Treatment completion (B)-(*written by Carrie Lethborg- oncology social worker*)
7. A patient’s guide: Follow up for breast cancer (I) -(*American Society of Clinical Oncology*)
8. Tamoxifen –(B)-(*written by Medical Oncologist Dr Jacqui Chirgwin*)
9. Reducing my risk of lymphoedema -(*Breast Cancer Action Group*)
10. If you or someone you know has cancer, a cancer support group could help (P)- (*ACCV*)

(B)=booklet (P)=pamphlet (I)=Internet source

- 11. Living with cancer education program (P)- (ACCV)**
- 12. Cancer services in Victoria (B)- (ACCV)**
- 13. Understanding emotions (B)-(*Qld. Cancer Fund*)**
- 14. Cancer and complementary therapies (B)- (*WA Cancer Fund*)**
- 15. Surfing the net – a ‘safety guide’ for people living with cancer (P)-(*Carrie Lethborg*)**
- 16. Breast care nurses-supporting people experiencing breast cancer (P)- (ACCV)**
- 17. ACCV-How we can help (P)- (ACCV)**
- 18. Making decisions about Hormone Replacement Therapy (P)- (ACCV)**
- 19. Exercises for Recovery (P)- (*Qld. Cancer Fund*)**

(B)=booklet (P)=pamphlet (I)=Internet source

APPENDIX B

Evaluation of information packages

Structured interview questions

This is Spiri Galetakis from the BSEP. I have been working on a project to assist doctors and nurses to deliver written information to their patients. I understand that a few weeks ago you were given a package of information relating to breast cancer. I'm interviewing women about what they thought about that information package. The doctor/ BCN said that you had agreed to being contacted. The interview normally takes about 5 minutes and your answers are completely confidential. Would it be okay to interview you now? At any point in the interview if you are feeling tired or distressed please say so and we can end the interview.

1. Who gave you the package of information?

- BCN
- Doctor
- Other

2. How was the information given to you and at what point (eg before or after treatment completion) ?

- Information was offered by the BCN/ Doctor
- Patient requested information from the BCN/ Doctor
- At the diagnosis consultation
- After the diagnosis consultation
- At a review consultation (+/- post operatively)

3. Was it the right time to get information?

- Yes
- No

If no: would it have been better to get information sooner, later or just at a different moment?

- Sooner
- Later
- Different moment

4. When you were given the package, what did you expect it to contain?

- Not sure
- Information about my cancer
- Information about treatment options
- Information about support available
- Other

5. How much of the information if any did you read?

- All of it thoroughly
- All of some booklets but not others
- Most of all the booklets
- Skimmed through most booklets
- None of it

6. Did any of your family/ carers/ friends read the information?

- Family- husband/ children
- Carers
- Friends

7. Was there anything that you found upsetting or wished you hadn't read?

8. What information was not available in the package that you would have liked?

9. Was there enough information to guide you to further sources of information if you wanted more?

- Yes
- No

10. Other comments

APPENDIX C

RESULTS OF CONSUMER SURVEY

Table 1: Provider of information package

Provider of package	No. of women receiving diagnosis package	No. of women receiving treatment completion package
Surgeon	2	0
BCN	2	20
Other	1 (Secretary)	3 (RT Nurse)
Total	5	23

Table 2: Point in time package received by woman

Point in Disease Continuum	Diagnosis Package	Treatment Completion Package
Diagnosis	2	
Post Surgery	3	
During Radiotherapy		8
Post Radiotherapy		15
Total	5	23

Table 3: Suitability of package timing according to women

Suitability Of Timing	Diagnosis Package	Treatment Completion Package
Right Time	3	10
Wrong Time	2	10
Unsure	0	3
Total	5	23

Table 4: Women's preference for package timing

	Diagnosis Package	Treatment Completion Package
Sooner	0	11
Later	2	0
Different Moment	0	1

Table 5: Women's expectations of the information packages

	Diagnosis Package	Treatment Completion Package
Info Re Breast Cancer, Treatment & Support	3	9
General Cancer Info	1	5
Unsure	1	9

Table 6: Level of information read

	Diagnosis Package	Treatment Completion Package
All Of Package	1	5
All Of Select Resources	2	10
Most Of Select Resources		3
Skimmed Through Most Resources	2	4
None		1