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"Assessing the effectiveness of computerised dissemination of the "NHMRC Clinical Guidelines for the Management of Early Breast Cancer"."

(Medical Oncologists' Guidelines Dissemination Project)

Baseline Report

July, 1998

A Report Prepared for the National Breast Cancer Centre

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"Assessing the effectiveness of computerised dissemination of the "NHMRC Clinical Guidelines for the Management of Early Breast Cancer".

Table of Contents

Introduction

In 1995, the National Health and Medical Research Council (NHMRC) launched the “Clinical Guidelines for the Management of Early Breast Cancer” (1). These guidelines aimed to provide breast cancer specialists with evidence-based information and recommendations for best practice in relation to the management of women with early stage breast cancer. It was intended that the NHMRC guidelines be adopted by surgeons, medical oncologists, radiotherapists, general practitioners and other health care providers involved in the management of women with early breast cancer. The next step in the implementation of the NHMRC guidelines is their effective dissemination to relevant health care providers.

Relatively little is known about how best to encourage the implementation of clinical practice guidelines. A recent review of the effectiveness of guidelines at affecting clinical practice concluded that more active methods of dissemination, such as the use of computer prompting or reminder and feedback systems were more effective than simple postal dissemination of guidelines (2). However, no previous studies have involved breast cancer care guidelines.

Therefore, this project aimed to assess the effectiveness of a computerised method of disseminating the NHMRC Guidelines for the Management of Early Breast Cancer. For the sake of brevity, these will be referred to as "the Guidelines" throughout this report. More specifically, the study aimed to assess the effectiveness of printed feedback from an interactive touchscreen computer program at increasing the proportion of medical oncology patients with early breast cancer who are treated in accordance with the Guidelines. The study focused on providing tools to assist medical oncologists in providing a level of care as outlined by the NHMRC, by accessing the recommendations contained in the Guidelines.

This study provided an opportunity to explore one strategy which could potentially be effective at implementing guidelines in a clinical setting, while also attempting to ensure all women diagnosed with early breast cancer receive optimal treatment.

A subset of the Guidelines considered most relevant to medical oncologists and their patients have been used as outcome measures, indicating the interactive computer program’s effectiveness. The acceptability of the interactive computer program, to patients and medical oncologists, was also assessed in study, although results have not been presented in this report. The aims of this report were to document the development of the project and to report on the

baseline levels of treatment in accordance with the Guidelines. This report presents data collected for the baseline period only.

Method

Design

This project employed a multiple baseline design, whereby each medical oncology unit acted as its own control. The intervention was introduced into each unit at a different time to control for any changes occurring outside of the trial. Each unit nominated a convenient starting date within the multiple baseline schedule. A multiple baseline design was chosen in preference to a randomised, controlled trial because the method of using interactive computers as a means of disseminating guidelines has not been widely studied. Although a randomised, controlled trial would have the power to provide more conclusive results, it would have necessitated involving a much larger number of medical oncology units and patients in order to assess the effectiveness of the method. Therefore, it was considered prudent to conduct this type of pilot study prior to a full-scale efficacy trial.

It was expected that each unit would see between five and 15 early breast cancer patients a week, a sufficient number to allow the detection of any significant changes in treatment practices. The number of women recruited from each medical oncology unit was anticipated to vary, depending on the number of women seen with early breast cancer. Data collection was set to run for 16 weeks: 6 baseline weeks and 10 intervention weeks. This was expected to allow adequate time to collect data for enough patients, given that the majority of breast cancer patients have chemotherapy in three week cycles, allowing multiple opportunities for feedback to be acted on.

Outcome Measures

The process involved in determining the outcome measures required two steps. Firstly, it was necessary to establish which recommendations from the Guidelines could be translated into questions. Once these questions had been determined, questions had to be grouped appropriately. A large proportion of these questions could be answered by the patients, however, a subset of questions would have to be answered by a medical oncologist, as not all patients would have information on the details of their diagnosis and treatment regimens.

Therefore, data collection for this study included three main components: a computerised patient survey, including acceptability questions, a diagnostic information form (completed by medical oncologists) and a paper survey of the acceptability of the interactive computer program to unit staff. All three components represent outcome measures, and are discussed below:

Outcome measures: The patient survey

The patient survey was developed by a collaborative process, involving the project team, the participating medical oncologists and a computer programmer. Initially, the project team and the oncologists were involved in a process of reaching consensus about which recommendations from the Guidelines should be evaluated in the project. The Guidelines were firstly summarised into point form. A subset of guidelines considered most relevant to medical oncologists and their patients were selected from the summarised guidelines. For example, the Guidelines provide a list of information issues (p.17) that women with breast cancer need, including: the causes and extent of the disease; the time and cost involved in having treatment and the effect of cancer on interpersonal and sexual relationships. These issues were included in the initial summary list of the Guidelines, as each issue was considered to be relevant to women being treated in a medical oncology unit.

Next, these relevant guidelines were translated into questions. Using the previous example, questions were designed to assess the adequacy of the information received regarding each topic, such as "what is your level of need for information about the causes of breast cancer?" and "what is your level of need for information about your own type of breast cancer?".

Existing studies with breast cancer patients were examined to look at the way items had been phrased, including typical response options. Existing studies which had used touch screens were also examined to determine how to model the logic flow of the patient survey.

As a result of these initial steps, the patient survey was designed to ask women with breast cancer a range of questions specific to their reasons for attending the medical oncology unit. These reasons may be broken down into three categories:

- initial consultations with an oncologist to discuss the possibility of receiving adjuvant treatment;
- treatment sessions of adjuvant therapy;
- follow-up consultations with the oncologist, after the completion of adjuvant treatment.

The survey, which took an average of 15 minutes to complete, included questions based on the Guidelines. The questions included in the patient survey were from the Guidelines topic areas such as: the aims of having treatment; communication between the medical oncologist and the patient's GP; information needs; being informed of clinical trials; counselling and support; making treatment decisions; being advised about tamoxifen; and follow-up. For each topic area, at least one question asked patients if these issues from the Guidelines had been either discussed or offered during their treatment. Follow-up patients answered a questions about their treatment from a retrospective point of view; questions specifically about follow-up care were phrased in the present tense.

At the end of the survey, all breast cancer patients were asked to use the computer again the next time they attended the medical oncology unit. Subsequent surveys were then tailored to ask the patient questions dependent on the responses they gave on their previous visit. For example, if a patient indicated that they were satisfied with information given on the possibility of participating in a clinical trial, this answer was stored in the computer database in such a way that this question was not presented the subsequent time(s) the survey was attempted.

Outcome measures: Diagnostic information form

As many patients do not know the details of their cancer type and their treatment regimens, it was necessary to devise a method for collecting specific diagnostic and treatment information for each individual patient. Therefore, a standardised form for clinicians to complete for each patient was developed (see Appendix 1). The diagnostic information form was produced by the computer for each eligible patient and included their name, date of birth and date of the consultation. The clinician entered the following data for each individual patient: their stage of disease at diagnosis, including the TNM staging, where available; their menopausal status; their node status; their oestrogen receptor status; the drugs prescribed (names, doses & regimes). Clinicians returned the completed diagnostic information forms to the project team on a weekly basis.

Outcome measures: Acceptability of the interactive computer program

In order to assess the acceptability of the interactive computer program to patients, additional questions were included at the end of the patient survey. These questions are asked only once of each patient, on the second time they completed the survey. At the conclusion of the intervention, medical oncologists and nursing staff will be asked to complete a brief survey giving their perceptions about the acceptability of the interactive computer program.

Feedback

Inherent in the aims of this study was the goal to provide individual patient feedback to oncologists. Two forms of feedback were developed and represent the interventions for the project. The first type of feedback was an individualised summary feedback sheet that was automatically printed out by the computer and placed in the patient's file before they saw the clinician (see Appendix 2). This feedback, which was based on patients' responses both summarised and highlighted the most important issues for the patient on that particular day.

The second form of feedback, also given to clinicians during the intervention phase, was based on the information provided in the diagnostic information forms (see Appendix 3). Using a standard coding method, a member of the research team checked the diagnostic and treatment information against the Guidelines to determine for each patient whether…

- the woman was diagnosed and/or treated in accordance with the Guidelines;
- the woman was not diagnosed and/or treated in accordance with the Guidelines;
- it was not possible to determine (from the information provided) if the woman was diagnosed and/or treated in accordance with the Guidelines.

This feedback was then mailed back to the medical oncology unit, within 5 working days, and inserted into the patient's file prior to their next visit, for the oncologist's information.

Recruitment: Medical oncologists

A convenience sample of oncologists were invited to participate in the research. One of the project co-investigators initially approached oncologists working in five medical oncology units across Australia. All five oncologists approached accepted the invitation to participate in this research. The oncologists were notified of the various tasks involved in the project, including: reviewing the questions to be included in the patient survey and diagnostic information form; providing information on patient numbers in their medical oncology unit; nominating a member of staff in their unit who could assist with the day to day running of the project, and facilitating the installation process when the touch screens were installed in each unit. A series of teleconferences were then organised to ensure full participation from all involved. Each oncologist was requested to recruit the support of other oncologists and nursing and reception staff working in their medical oncology unit. Such recruitment was encouraged from the initial stages of the project in an attempt to ensure the project would be well established in the minds of the oncologists and other staff prior to the commencement of data collection.

During the development of the computer program, each oncologist contributed to the content of the patient survey and the diagnostic information form by providing comments and suggestions. Throughout the development phase, collaborating oncologists were also consulted about the practical issues within their unit, which would help to determine the process for installing the computers and training unit staff. Regular updates were also given to clinicians to inform them of progress during the programming of the interactive computer program. Finally, each collaborating oncologist also facilitated in the process of gaining ethics approval from their institution.

Recruitment: Oncology patients

All breast cancer patients attending the medical oncology unit received an information letter explaining the project from one of the clinic staff members. The clinic staff member's position varied across the units and was either clinical trial coordinator, nursing unit manager, clinical nurse consultant or receptionist. All breast cancer patients were asked to participate in the study, as many patients would not know if their diagnosis was classed as early or advanced stage. The diagnostic information form was later used to determine and categorise individual patients' disease stage.

Patients were required to give their consent in order to be involved in the study. Consent was obtained in a series of questions presented on-screen. Each time the patient survey was attempted, one consent screen was presented at the beginning of the survey, asking patients if they were happy to participate. Similarly, three consent screens were also included at the conclusion of the patient survey, asking for permission to use the person's responses for this project, asking that diagnostic information be accessed from the person's medical records and, finally, that the person's doctor be given the printed feedback sheets during the intervention phase. This on-screen consent was considered adequate by most of the participating units; one unit required patients to also sign a paper consent form before completing the survey, due to ethics committee requirements.

Consenting breast cancer patients then answered the survey on the computer while waiting for their consultation with an oncologist. If the patient was called for treatment while completing the survey, a "STOP" button was selected, which returned the computer to the initial introduction screen, ready for the next patient. The patient could then complete the survey at the end of their consultation by re-entering their ID and the computer returned to the position where the survey was interrupted.

Installation of the touch screen and training of staff

Computers were delivered to each medical oncology unit prior to the commencement of data collection. A research assistant employed by the project team was present in each unit for the first week of data collection. The research assistant was required to liaise with the oncologists and staff in each unit to determine the most appropriate location of the touch screen within the waiting area, and the location of the printer in a secure and convenient location so that the diagnosis information forms and the individualised feedback summary sheets could be immediately inserted into patients' files on completion of the survey. The research assistant then trained the oncologists and the unit staff, using a procedures manual, which detailed the specific instructions for using the computer, including how to deal with malfunctions. The patient survey was demonstrated and explained to all staff members. Since the beginning of data collection, contact has been maintained on at least a weekly basis with one staff member, nominated as project liaison person, involved in the project at each unit. This has helped to ensure any problems or difficulties were quickly resolved.

Programs, data, analysis and statistics

The patient survey was written using Microsoft Access, which automatically stored response data in a collection of tables. Therefore, no separate data entry procedure was required before the data analysis: patients directly entered the data into the database and editing of responses was not necessary, reducing error bias. The data were then exported into the SAS computerised statistical program for statistical frequencies and were analysed. Basic descriptive analyses were conducted to produce frequencies of the reported questions drawn from the Guidelines. Participants' demographic and treatment history characteristics were also analysed.

Baseline Results

Participating Oncologists

Oncologists from five medical oncology units agreed to participate: Royal Adelaide Hospital (SA); Nepean Hospital (Penrith, NSW); Sir Charles Gairdner Hospital (Perth, WA); Princess Alexandra Hospital (Brisbane, QLD) and The Wesley Hospital (Brisbane, QLD). Due to logistical problems with installing the computer facilities, one hospital (Wesley) had to withdraw prior to the data collection phase. Since the installation of the touch screen computers in the remaining four medical oncology units, one medical oncology unit (Princess

Alexandra) had difficulties recruiting adequate patient numbers. As a result, this unit recommenced baseline collection and recruitment figures have improved to an acceptable level. One hospital (Nepean) did not have adequate patient numbers to collect data at the anticipated weekly levels. The results from these patients have been included in this baseline report, however, are unlikely to contribute to the final analyses.

Breast Cancer Participants' Characteristics

Over the six week baseline period, 79 women completed the patient survey at least once across the three units. A proportion of these 79 women also answered the survey again on subsequent visits to the unit. The remainder of this baseline report presents results only for the first completed survey for each patient. This report also includes information for all breast cancer patients, as diagnostic information will not be complete until the conclusion of the study. The first section includes tables presenting the demographic frequencies for the sample. The second section includes frequencies in relation to diagnostic and treatment guidelines. The third section includes frequencies for specific guideline issues. Furthermore, the third section only includes information for patients currently attending for treatment or follow-up appointments, as patients attending for an initial consultation with their medical oncologist would not yet have had an opportunity to be treated in accordance with the Guidelines.

Section One: Describing the sample

The sample size was on the lower end of initially projected estimates (5-15 patients each week in each hospital). The number of new patients attempting the survey each week was averaged at 4 patients each week in three units (Adelaide, Brisbane, Perth). The average number of patients completing the survey each week was higher given that some patients returned to complete the questionnaire a second or subsequent time. The number of patients completing the survey was considerably higher in the first few weeks of data collection and then declined as the study continued.

Table 1.1 displays the number of patients with early versus advanced breast cancer participating in the study. The majority of the sample (62%) were early breast cancer patients. Diagnosis was based on the Guidelines, using the diagnostic information completed by the medical oncologists.

Table 1.1 Baseline number of participants by medical oncology unit and by disease stage at diagnosis

Hospital	Early	Advanced	Information Missing	Total Baseline	
	N	N	N	N	%
Adelaide	8	6	8	22	28
Brisbane	14	7	4	25	32
Nepean	5	1	2	8	10
Perth	14	5	5	24	30
TOTAL	**41**	**19**	**19**	**79**	**100**

Specific information regarding patients' reasons for visiting the oncology units, when patients were first diagnosed with breast cancer and past treatment histories are collated in Table 1.2. The majority of patients attended for treatment sessions or follow up sessions. The participants' reported time since being first diagnosed with breast cancer was fairly evenly distributed. The most common forms of past treatment were chemotherapy, surgery and radiotherapy.

Table 1.2 Disease and treatment information

	% of all participants (n=79)
Reason for visiting oncology unit	
Initial consultation with oncologist	4
Treatment session	53
Follow-up visit	43
First diagnosed with breast cancer	
Less than 6 months ago	32
Between 6 months and 2 years ago	27
More than 2 years ago	42
Past treatments*	
Surgery - all types	84
Chemotherapy	86
Hormone therapy	30
Radiotherapy	65
Ovarian treatment	3

* totals more than 100% as patients will have received multiple treatment modalities.

Table 1.3 presents demographic characteristics of the sample. The median age of the participants was 55 years, ranging from 31 to 75 years. Women who completed the survey were typically married or living with a partner and were employed in the work force either full or part-time. Education level completed was broadly distributed.

Table 1.3 Demographic characteristics of the sample

	% of all participants (n=79)
Age (source: date of birth)	
18-49	54
50-70+	46
Current marital status	
Married/Living with partner	80
Divorced/ separated/ widowed/ single (never married)	20
Level of education	
Didn't complete high school	17
Year 10 equivalent	45
Year 12 equivalent	13
Trade/ technical/ university/ other	25
Usual employment situation	
Employed full time or part time	47
Home duties	29
Student	3
Retired / unemployed/ unable to work/ other	21

Section Two: Diagnosis and treatment guidelines

This section presents frequencies for the proportion of patients being diagnosed and treated in accordance with the Guidelines across the six week baseline period and combined across all four units. At this stage of the study, there are insufficient data about treatment for small proportion of patients; this information will be sought from each hospital prior to the conclusion of the study.

Diagnosis

The Guidelines provide information on the most widely used information on how breast cancer is classified - the TNM clinical classification. TNM classifications are utilised to assign stage groupings (ie. Stage I, II, III, IV) to cases of breast cancer. These stage groupings are used to determine whether a woman's diagnosis is generally classified as "early breast cancer" or "advanced breast cancer". Participating clinicians were asked to indicate each patient's TNM classification along with their assigned stage grouping and general classification on the diagnosis information forms (refer to Appendix 1). The clinicians' responses were then compared to the staging instructions in the Guidelines which are summarised in Appendix 3. Table 2.1 presents information on how closely each patient's stage grouping and general classification corresponded with the Guidelines as based on their TNM data. The results

indicated that in terms of stage grouping, over one third of patients were assigned a stage group which was in accordance with the Guidelines; only a very small proportion of patients were assigned a stage that was contrary to the Guidelines. For approximately half the sample, a stage grouping could not be determined, as either the diagnostic information form had not been returned or information on the form was insufficient.

Table 2.1: Agreement between oncologists and Guidelines regarding patients' stage grouping and general classification, based on their TNM data

	% of all participants (n=79)
Stage grouping	
Assigned stage agreed with Guidelines	42
Assigned stage was earlier than Guidelines	5
Assigned stage was later than Guidelines	1
Insufficient information to assess agreement	29
Diagnostic information form not returned	23
General classification	
Classified as early, in agreement with Guidelines	33
Classified as advanced, in agreement with Guidelines	15
Classified as early, contrary to the Guidelines	6
Classified as advanced, contrary to the Guidelines	15
Insufficient information to assess agreement	8
Diagnostic information form not returned	23

Treatment

Table 2.2 displays information about the two types of treatment received by patients (hormone therapy and chemotherapy) and whether these treatments were in accordance with the Guidelines, based on each patient's menopausal, node and receptor status. Again, for a third to half the sample, it was not possible to determine if treatment regimens were in accordance with the Guidelines due to insufficient or missing information. Only a small proportion of patients with early breast cancer were given treatment regimens not in accordance with the Guidelines.

Table 2.2: **The proportion of patients who received chemotherapy and tamoxifen regimens in accordance with the Guidelines, based on their menopausal, node and receptor status**

	% of all participants (n=79)	
	Chemotherapy	***Hormone therapy***
	(%)	(%)
Early breast cancer patients		
Treatment regimens were in accordance with recommended Guidelines	36	23
Treatment regimens were <u>not</u> in accordance with recommended Guidelines	5	9
Advanced breast cancer (not applicable)	24	24
Insufficient information to determine	12	21
Diagnostic information not returned	23	23

Section Three: Specific guidelines by topic

In this section, analyses are presented by topic in order of how issues are likely to arise during the course of a woman's breast cancer experience, rather than how they appear in the Guidelines. Given the broad range of patients included in this study, not all issues were relevant for all patients. Therefore, each table indicates the women considered eligible by quantity and visit type. Please note that, for some tables, totals do not equal 100%, as figures have been rounded.

Aims and nature of treatment

The Guidelines state (p. 11) that "the aim of treatment should be discussed by the woman and her doctor" and also indicate that women should be given information about the process or steps involved in having treatment (p. 17). Table 3.1 shows that participants were generally satisfied with the information received about the aims of treatment and about the steps that would be involved.

Table 3.1: Women's satisfaction with information about the aims of and steps involved with treatment

	Aims of having treatment	Steps involved with treatment
	% of women in current treatment (n=42)	% of women in current treatment or follow-up (n=76)
Satisfied	91	91
Wanted more information	9	8
Received more information than wanted	0	1

Making treatment decisions

The Guidelines state that all women "should be encouraged to participate in the selection of surgical and subsequent treatment and should be informed fully about the appropriate treatment options (p.33)." Furthermore, the Guidelines state that "only if the woman delegates her decision to the doctor is the doctor entitled which form of treatment to pursue (p.9)." Table 3.2 shows that participants were generally happy with their participation in making decisions about their treatment.

Table 3.2: Women's satisfaction with their level of involvement in treatment decisions

	% of women in current treatment or follow-up (n=76)
Happy with involvement	92
Wanted to be more involved	7
Wanted to be less involved	0
Not sure	1

Clinical trials

The Guidelines say that all women diagnosed with early breast cancer should be encouraged, in a non-coercive manner, to participate in clinical trials for which they are eligible. (insert page ref). Table 3.3 displays the proportion of women who were given information about clinical trials. Approximately one third of the sample were given information about clinical trials, almost half of the sample were not given any information and wanted this.

Table 3.3: Women's satisfaction with information about clinical trials

	% of women in current treatment (n=42)
Satisfied with information given	31
Wanted information, but received none	45
Not concerned	24

Tamoxifen

The Guidelines say that all women diagnosed with early breast cancer who are offered tamoxifen as a possible treatment should be aware of the potential side effects (p. 80-81). Table 3.4 displays the responses for this issue.

Table 3.4: Women's reported level of information about tamoxifen and potential side effects

	% of post-menopausal women in current treatment (n=10)
Told of potential side effects and taking tamoxifen	10
Told of potential side effects and NOT taking tamoxifen	20
Not told and would like information	40
Not told and doesn't want any information	30

Communication between general practitioners (GPs) and specialists

The Guidelines section entitled "Choosing a specialist" includes recommendations about the necessity of communication between a woman's GP and specialists: "general practitioners

require prompt, clear information in writing about management decisions, follow-up plans and patient progress." (p. 22) Table 3.5 shows a high degree of concordance with this guideline, with more than three quarters of general practitioners being notified by specialists.

Table 3.5: The proportion of women for whom their GP had been informed of their treatment

	% of women in current treatment or follow-up (n=76)
GP informed	82
GP not informed	7
Does not have regular GP	1
Not sure	11

Information

There are several issues within this section of the Guidelines that have been reported here. Firstly, the Guidelines indicate that for all women diagnosed with early breast cancer "information should be provided in a form and manner which helps patients understand the problem and treatment options available, and which is appropriate to the patient's circumstances, personality, expectations, fears, beliefs, values and cultural background." (p. 16). Table 3.6 reports on the overall level of satisfaction women reported in regards to the information they received during their treatment, showing a high degree of satisfaction.

Table 3.6: Women's satisfaction with overall level of received information

	% of women in current treatment or follow-up (n=76)
Happy with information received	75
Not enough information received	24
Too much information received	0
Did not receive any information	1

The Guidelines also state that in women should be offered information on a range of topics "…about the psychosocial impact of breast cancer and the material and practical resources required to adjust to and cope with the disease ." (p.17). Information topics listed include: the causes of breast cancer, the extent of breast cancer, the woman's type of breast cancer, the chances of having a recurrence, and the chances of being cured, the benefits and risks with certain treatments. Table 3.7 reports women's satisfaction levels with the information they received for specific issues, indicating more room for improvement than the general rating above. As the Guidelines also state that women may choose to refuse any information (p.16),

women also had the option to indicate they wanted less information on each issue but this option was never chosen.

Table 3.7: Women's satisfaction with information on specific issues

	% Satisfied	% Wanted more information	% Issue not a concern
Treatment and follow-up patients **(n=76)**			
Extent of breast cancer in the community	59	37	4
Causes of breast cancer	55	42	3
Own type of breast cancer	49	51	0
Chances of being cured	34	64	1
Chances of having a recurrence	26	72	1
Treatment patients only **(n=42)**			
Benefits & effects of chemotherapy	62	33	5
Benefits & effects of hormone therapy	29	50	21
Follow-up patients only **(n=34)**			
How often check-ups are needed	56	41	3
How breast cancer may affect other women in the family	29	59	12
Knowing whether future tests will be needed	24	74	3

Another guideline from the information section says that doctors could "…tape record the initial consultation and give it to the women to play later." (p. 19). Table 3.8 shows that although few women were offered such tapes, more than half reported not wanting one. However, over a third of patients responded that they would have liked a tape recording.

Table 3.8: The proportion of women who received a tape recording of the initial consultation

	% of women in current treatment or follow-up (n=76)
Offered a tape recording	4
Didn't receive a tape, but would have liked one	38
Did not want a tape recording	54
Doesn't remember (follow-up only)	4

Written treatment plans are another item that the Guidelines state doctors should provide to their patients (p.18). Table 3.9 shows a low rate of adherence to this Guideline and a higher level of need among patients.

Table 3.9: The proportion of women who received a written management plan

	% of women in current treatment or follow-up (n=76)
Received a written treatment plan	18
Received a plan, but would have liked more information	5
Did not want a management plan	32
Didn't receive a management plan but wanted one	42
Doesn't remember (follow-up only)	3

The patient survey also asked women who were attending for follow-up consultations how satisfied they were with the information provided during their treatment. Table 3.10 displays results for information issues which follow-up participants rated. This table indicates that more than three quarters of all patients retrospectively assessed the information provided during treatment as satisfactory. Some patients would have preferred more information about tamoxifen and it's possible benefits. A very small proportion of patients responded that they would have preferred less information for one issue: the likely outcome of health.

Table 3.10: Follow-up patients satisfaction with information provided during their treatment

	% of women in follow-up (n=34)			
	Satisfied	Wanted more information	Wanted less information	Not satisfied
About likely outcomes of health	88	6	3	3
About possible treatment options	85	15	0	0
Total amount received during treatment	77	21	0	3
On possible side effects before commencing treatment	77	21	0	3
Tamoxifen and its possible benefits	71	29	0	0

Counselling and support

Within this section, the Guidelines state that all women diagnosed with early breast cancer should be offered appropriate counselling and support. This may include referral to a counsellor, referral to a support group, help with transport, help with accommodation near the treatment centre or help with caring for her family (p.27). Table 3.11 reports the level of support offered and needed. The main issues for patients in treatment and follow-up were extra need for support dealing with the possible long term effects of breast cancer, expressing thoughts and feelings and contacting the Breast Cancer Support Service (BCSS). For issues asked of treatment patients only, help was most needed with financial issues. For issues asked of follow up patients only, the issue where more support was needed was for knowing how to have a healthier lifestyle.

Table 3.11: Women's levels of need for counselling and support

	Needs met	Needed more support	Issue not a concern
Treatment and follow-up patients **(n=76)**	%	%	%
Expressing thoughts and feelings	65	22	13
Contact the BCSS	57	17	26
Meeting a counsellor	53	13	34
Meet a support group	51	12	37
Possible long term effects	49	42	9
Treatment patients only **(n=42)**			
Help caring for others	24	21	55
Told about special clothing	19	5	76
Financial help	17	43	41
Accommodation near the hospital	5	0	95
Follow-up patients only **(n=34)**			
Being able to talk to others about your experiences	74	12	15
Told about how to have a healthier lifestyle	59	29	12
Help with any long term effects on family relationships	59	18	24

Again, follow-up patients were asked to also retrospectively assess how satisfied they were with the help offered in regards to counselling and support issues during their treatment. Table 3.12 shows patients' level of satisfaction for each issue. Approximately one third of all patients would have liked more help with accessing support groups, counsellors or psychologists, or the Breast Cancer Support Service.

Table 3.12: Women's satisfaction with help offered during treatment

	% of women in follow-up (n=34)			
	Satisfied	Satisfied, but wanted more information	Issue was not a concern	Doesn't recall
Breast cancer support services	69	28	3	0
Support groups	59	32	9	0
Social workers	47	21	27	6
Counsellors or psychologists	38	29	29	3

Follow-up

Chapter 8 contains specific guidelines for women who have completed treatment. The Guidelines state that all women diagnosed with early breast cancer should have a minimal follow-up plan. Table 3.13 displays information on the whether follow-up plans were offered. A large proportion of the sample received a written follow-up plan but about a quarter of these would have liked more information included in this plan.

Table 3.13: The proportion of women who were given a follow-up plan

	% of women in follow-up (n=34)
Received a follow up plan and was satisfied with this	62
Received a follow up plan but wanted more information	18
Did not receive a plan and would have liked one	18
Did not receive a plan and didn't want one	1

The Guidelines also provide a table (p.101) which recommends a follow-up schedule that should be observed, which can be applied to women who have completed chemotherapy or hormone therapy. In summary, it states that a history and examination should be undertaken according to the amount of time since treatment was completed: 0-1 years: every 3 months; 1-5 years: every six months; after 5 years: every year. Table 3.14 provides information on how often the participants in follow-up had presented for a follow-up consultation with a medical oncologist. Follow-up appointments scheduled at appropriate intervals were reported for the large majority of follow-up patients; only 3% of the sample had not been seen for a follow up appointment in accordance with the recommended guidelines.

Table 3.14: The proportion of women who had a follow-up consultation and length of time

	% of women in follow-up (n=34)		
	Length of time since treatment completed:		
	Up to 12 months %	1-5 years ago %	More than five years %
First follow-up visit with doctor since treatment completed	18	0	0
Second or subsequent visit with doctor; length of time since last follow-up visit	0	0	0
1-3 months ago	41	8	0
4-6 months ago	6	12	0
7-9 months ago	0	8	0
10-12 months ago	0	0	3
13-18 months ago	0	0	0
> 18 months ago	0	3	0

Discussion

The results presented in this report give an initial indication of the baseline levels of breast cancer patients' treatment in accordance with the Guidelines for four medical oncology units across Australia.

Before discussing the results in detail, several points should be noted. As this report provides findings for the first six weeks of data collection only, the reported frequencies provide only general trends for specific guideline items. The report to be presented on the full data collection will give final indications on the significance of this study. More specifically, the results presented in section two, that is the diagnostic and treatment frequencies, provide a very general indication only, as data collection in this phase is not completed.

The baseline results suggest that a large majority of women with breast cancer are satisfied with the over-all aspects of their care, particularly in regards to issues such as being told about the aims of treatment, making decisions about treatment, and being satisfied with the amount of information given, and communication between their general practitioner and their specialist. This would suggest that many patients are receiving treatment in accordance with the recommendations contained within the Guidelines.

The baseline results do reveal some interesting trends. Respondents had particular concerns about certain issues presented throughout the survey items. The most noticeable from a first glance at the data is that many patients appear to have concerns with long term issues. This is demonstrated in Table 3.7 which asks patients about information issues; only a quarter of all participants were satisfied with the information they received about the chance of having a recurrence and only a third were satisfied with information about the chances of being cured. Similarly, three quarters of follow-up patients wanted more information on whether they would need any tests (for recurrences) in the future. Evidence from Table 3.11 also supports this trend, with almost half of all treatment and follow-up participants saying they wanted support on dealing with the possible long terms effects of their illness, but have not received any support for dealing with this issue. Interestingly, nearly all patients in the follow-up group are receiving follow-up consultations in accordance with the Guidelines. The baseline results appear to suggest that such appointments may not provide adequate opportunities for patients to discuss their concerns about the long term effects of their illness with their oncologist.

Participants' satisfaction with the provision of information presents another interesting finding. When patients were asked if they were satisfied with the total amount of information they had received during their treatment, most reported they were satisfied. This finding differs substantially from previously reported levels of satisfaction for information received (3). This discrepancy could be attributed to patients' concerns about their medical oncologist having access to their survey responses. When patients were asked to rate their satisfaction for specific information items, including items that were more relevant to their current situation (treatment or follow-up), a greater discrepancy in satisfaction levels was detected. This would suggest that it is particularly important that future work in the area of eliciting patient satisfaction levels for information needs includes specific topics rather than asking patients to rate overall levels of satisfaction.

Providing patients with information about clinical trials is one area where improvements in clinical practice need to be focussed. Approximately one third of patients were satisfied with the information they were given on clinical trials, with nearly half reporting that they wanted more information. These results suggest that offering patients enough information to enable them to decide whether to participate in a clinical trial is important. It is important to note, however, that it may be the case that no clinical trials were being conducted when individual patients were attending each unit for treatment, thus, no information was offered.

Similarly, providing patients with information about different treatment types is an area where clinical practice could be improved: half of all current treatment patients stated that they wanted more information on tamoxifen and it's possible benefits and side effects. This could be due to recent media about tamoxifen and many women may have been ineligible, however, it does indicate a need for improved communication. Please note that this question was only asked of women who were in current treatment and were post-menopausal (n=10) and thus only a small proportion of women were eligible to answer this question. At this baseline stage, it is difficult to assess if the current frequencies are likely to be representative of the whole sample.

The Guidelines suggest that certain types of materials could be given to patients to assist them during their treatment and follow-up. Three survey items explored whether patients had received these materials: written treatment and follow-up plans and tape recordings of the initial consultation with their medical oncologist. Written management plans were far more likely to be provided to follow-up patients, with more than three quarters of participants

reporting that they had received such a plan. However, only one quarter of patients received a management plan during treatment, with close to one half indicating they did not receive a plan, but would have liked one. Similarly, only a very small proportion of patients reported that they had received a tape recording of their first consultation. It is interesting to note, however, that more than half of the participants reported that they did not want a tape recording.

In conclusion, the baseline results give encouraging findings, with the majority of patients receiving treatment in accordance with many of the Guidelines. There is, however, still room for improvement and we look forward to analysing the full dataset to assess whether the computerised feedback offers any assistance in this area.

References

1. National Health and Medical Research Council. Clinical Practice Guidelines: The Management of Early Breast Cancer. Australian Government Publishing Service. 1995.

2. Davis D, Thomson M, Oxman A, Haynes R. Evidence for the effectiveness of CME. A review of 50 randomised controlled trials. JAMA 1992;268:1111-7.

3. Degner LF, Kristjanson LJ, Bowman D, Sloan JA, Carriere KC, O'Neil J, Bilodeau B, Watson P, Mueller B. Information Needs and Decisional Preferences in Women With Breast Cancer. JAMA 1997;277(18):1485-92.

Appendix One: Patient diagnostic information form

Cancer Council

Medical Oncologists' Dissemination Trial

national breast cancer centre

PATIENT DIAGNOSIS RECORD SHEET - (BREAST CANCER PATIENTS ONLY)

PATIENT SURNAME: EXAMPLE **Date of Birth:** 01/10/50

FIRST INITIAL: A

TODAY'S DATE: 17/7/98

Date treatment commenced in this department : Completed:

Please circle the relevant answer for each point

I.	General classification:	EARLY	ADVANCED
II.	Menopausal status at diagnosis:	PRE	PERI POST
III.	Node:	POSITIVE	NEGATIVE
IV.	Oestrogen receptor:	POSITIVE	NEGATIVE

Treatment History/Status				
	NO	**YES**	If **YES**, please specify:	
surgery	0	0 ⇨	mastectomy 0	breast conserving surgery 0
chemotherapy	0	0 ⇨	regime	cycle
hormone therapy	0	0 ⇨	tamoxifen	other
radiotherapy	0	0	details, if known:	
ovarian therapy	0	0	details, if known:	

TNM Classification - please circle														
T Categories	TX	T0	Tis	T1	T1a	T1b	T1c	T2	T3	T4	T4a	T4b	T4c	T4d
N Categories	NX	N0	N1	N2	N3									
M Categories	MX	M0	M1											

Stage Groupings -							
please circle	Stage 0	Stage I	Stage IIA	Stage IIB	Stage IIIA	Stage IIIB	Stage IV

Appendix Two: Patient feedback print-out

Medical Oncologists' Dissemination Trial

PATIENT FEEDBACK SHEET - (BREAST CANCER PATIENTS ONLY)

PATIENT SURNAME: EXAMPLE **Date of Birth:** 01/10/50

FIRST INITIAL: A

TODAY'S DATE: 17/7/98

Patient is attending for a **treatment** consultation

This patient is currently undergoing:

chemotherapy hormone therapy

1. Patient preferences and satisfaction

information wanted about treatment choices?	satisfied with choices
satisfaction with involvement in treatment choices?	satisfied with involvement
satisfaction with information about steps of treatment?	satisfied
satisfaction with amount of info so far?	would like more information
satisfaction with detail about aims of treatment?	satisfied

2. Information needs

the chances of being cured	high need
the causes of breast cancer	low need
your type of breast cancer	no need
the extent of breast cancer in the community	low need
the chances of having a recurrence	no need
the benefits and side effects of hormone therapies	low need
the benefits and side effects of chemotherapy	no need
the pros and cons of taking part in a clinical trial	high need

3. Current need for help with

finding out how to join a support group	no need
any special clothing needed	low need
finding out about the breast cancer support service	high need
dealing with the possible long term effects for you	high need
feeling able to express your thoughts and feelings	no need
caring for children, elderly parents, or spouse	low need
finding out about how to meet with a counsellor	no need
finding out about financial assistance that may be available	high need

4. Other factors

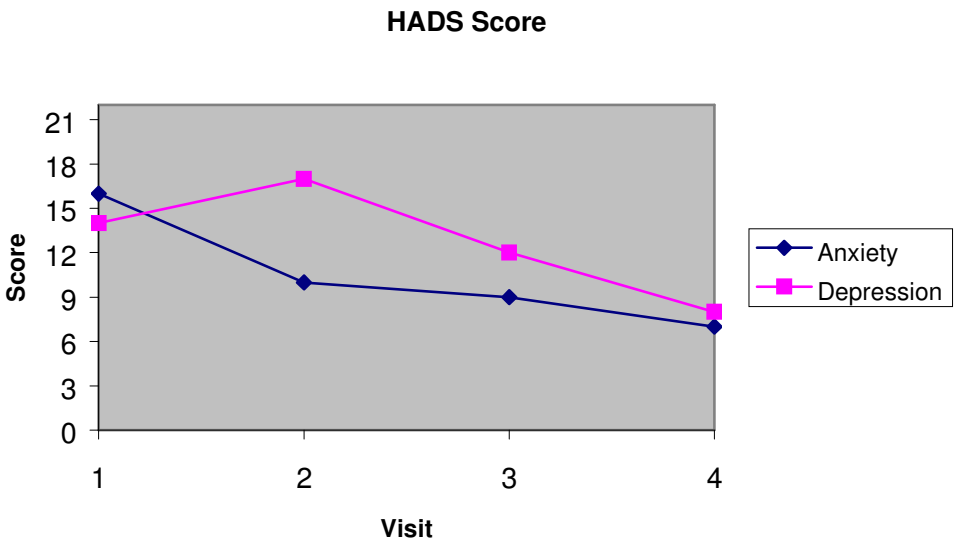
wants GP informed of treatment?	GP already informed
want a written treatment plan prepared by the doctor?	would like written treatment plan
want a tape recording of the doctor explaining treatment?	doesn't want tape
want a chance to ask questions?	Very important

SIDE EFFECTS of TREATMENT

SYMPTOM	TREATMENT	
	Session: 27/6/98	Today's Session: 17/7/98
• nausea	✓✓	✓
• vomiting		
• tiredness		
• constipation	✓✓	
• diarrhoea		
• hair loss		
• loss of appetite		✓✓
• skin rash		
• metallic taste in mouth		
• mouth sores	✓	
• hot flushes		

✓✓ Double tick indicates that the patient found this side effect debilitating

Anxiety and Depression: (0-7: low levels; 8-10 borderline levels; 11-21 clinical levels)



Appendix Three: Diagnostic feedback sheets

Patient's Details

Patient's Name: _____

Date of birth: _____

Date seen: _____

On their last Patient Diagnosis Record Sheet, the following information was recorded about this patient's diagnosis:		The Guidelines' classification, based on TNM data	Do you agree with the Guidelines?
TNM code:	**T= N= M=** missing		
Disease stage:	0 I IIA IIB IIIA IIIB IV missing	0 I IIA IIB IIIA IIIB IV can't tell	yes no can't tell
General classification:	early advanced missing	early advanced can't tell	yes no can't tell

- The indication of the patient's disease stage **IS / IS NOT in accordance with the Guidelines / CAN'T BE DETERMINED** due to missing information.
  - According to the Guidelines:

Stage	T code	N code	M code
Stage 0	Tis	N0	M0
Stage I	T1	N0	M0
Stage IIA	T0 T1 T2	N1 N1 N0	M0 M0 M0
Stage IIB	T2 T3	N1 N0	M0 M0
Stage IIIA	T0 T1 T2 T3	N2 N2 N2 N1, N2	M0 M0 M0 M0
Stage IIIB	T4 Any T	Any N N3	M0 M0
Stage IV	Any T	Any N	M1

- The indication of the patient's general classification **IS / IS NOT in accordance with the Guidelines / CAN'T BE DETERMINED** due to missing information.
  - According to the Guidelines:
    - Early = T1 or T2 **AND** N0 or N1 **AND** M0
    - Advanced = T3 or T4 **OR** N2 **OR** M1

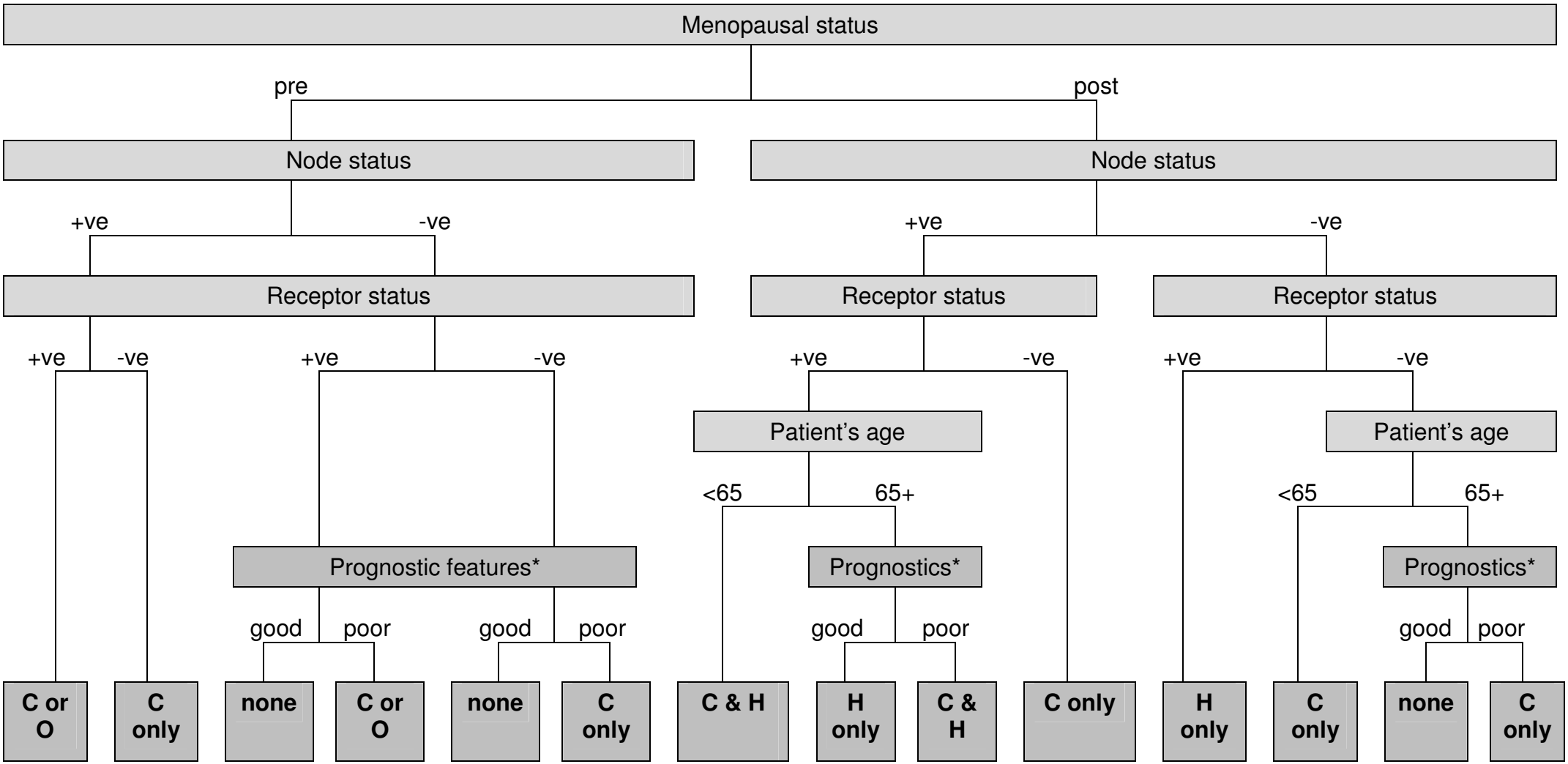
Medical Oncologists' Dissemination Trial: Treatment Feedback
(for patients with early breast cancer only)

On the last Patient Diagnosis Record Sheet, the following was noted about this patient's treatment history:					
Menopausal status:	pre	peri	post		missing
Node status:	+ve	-ve	unclear		missing
Receptor status:	+ve	-ve	unclear		missing
Age:		< 65 years		65+ years	
Systemic treatments:	***chemotherapy:***				
	none	CMF(P)	doxorubicin & cyclophosphamide	other	missing
	hormone therapy:				
	none		tamoxifen	other	missing
	ovarian therapy:				
	none		some		missing

- The patient's indicated treatment **IS / IS NOT in accordance with the Guidelines / CAN'T BE DETERMINED** due to missing information.

    - The flowchart on the back of this page summarises the NHMRC's recommendations regarding chemotherapy, hormone therapy and ovarian therapy, based on each patient's menopausal status, node status, oestrogen receptor status and, in some cases, their age.

Decision Flowchart of Appropriate Systemic Therapies: Early Breast Cancer Patients Only[1]



Treatment Key: **C** = chemotherapy (CMF or doxorubicin & cyclophosphamide), **H** = hormone therapy (tamoxifen), **O** = ovarian ablation

*** Prognostic features:** Poor prognostic features are defined as tumours > 20mm; or tumours 11-20mm with additional features such as oestrogen and progesterone receptor negativity, vessel space invasion or high histological grade.

1. NHMRC. *The Management of Early Breast Cancer: Clinical Practice Guidelines*. 1995