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# Assessing the effectiveness of computerised dissemination of the 'NHMRC's Clinical Guidelines for the Management of Early Breast Cancer': final report

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**(Medical Oncologists’ Guidelines Dissemination Project)**

**Final Report**

**December 1998**

**A Report Prepared for the NHMRC National Breast Cancer Centre**

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## **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 survey, completed by patients, 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 this study.

## **Method**

### **Design**

This project used a multiple baseline design, whereby each oncology unit acted as its own control. The intervention was introduced in 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. This 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 had greater power to detect changes, 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.

Each unit was expected to see between five and 15 early breast cancer patients a week, sufficient 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 were grouped appropriately. Although the majority of these questions could be answered by the patients, a subset of questions required input from patients' oncologists. This subset included information about patients' diagnoses and treatment regimens. This information was collected on standardised forms, produced automatically by the computer at the end of each relevant patient's completion of the computer survey (see Appendix 1). The development of the computer survey and of these forms is described in detail in the baseline report from this study (3).

### **Process measures**

The acceptability of this intervention, to patients, was assessed using some extra questions included at the end of patients' survey the second time they completed it. At the end of the intervention phase, medical oncologists, nursing and reception staff were also asked to complete a brief paper survey giving their perceptions about the acceptability of the intervention.

## **The feedback**

Two forms of feedback were developed for this project. The first type of feedback was an individualised summary feedback sheet that was printed automatically by the computer and placed in the patients' files before they saw their oncologists. This feedback, which was based on patients' responses to the computer survey, both summarised and highlighted the most important issues for each patient on that particular day. An example of a completed feedback sheet is included in Appendix 2.

The second form of feedback, also given to clinicians throughout the intervention phase, was based on the information provided by the oncologists on the diagnostic and treatment information forms mentioned earlier. Using a standardised coding method, a member of the research team checked the diagnostic and treatment information against the Guidelines to determine for each patient whether...

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

This feedback was then mailed back to the medical oncology unit, within five working days, to be inserted into the patient's file prior to their next visit. An example of this feedback is included in Appendix 3.

## **Recruiting the medical oncologists**

A convenience sample of oncologists, working in five medical oncology units across Australia, were invited to participate by one of the co-investigators. All five senior oncologists approached accepted the invitation to their Unit to participate and took an active role in the development of the project materials.

## **Recruiting the patients**

All breast cancer patients attending each participating 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 classified as of an early or advanced stage. The diagnostic and treatment information form was later used to determine and categorise individual patients' disease stages. Generally, patients gave their consent to participate by a series of questions presented on the computer. However, one unit required patients to also sign a paper consent form before completing the survey, due to ethics committee requirements. Consenting breast cancer patients answered the survey on the computer while waiting for their consultation with an oncologist.

A research assistant was present in each unit for the first week of data collection. Their tasks were 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 minor malfunctions. The patient survey was demonstrated and explained to all staff members. Throughout data collection, contact was maintained on at least a weekly basis with a staff member, nominated as project liaison person, at each unit.

## **Results**

Throughout the 16 weeks of data collection, a total of 121 separate women with breast cancer completed the computer survey at least once. Of these, 87 completed their first survey during the baseline phase and 34 completed their first survey during the intervention phase. Across the four hospitals, 27 women completed the computer survey more than once: 19 women completed it twice, five women completed it three times, two women completed it four times and one woman completed it six times. Unfortunately, these numbers were considerably less than expected, making traditional time series analyses, as planned, inappropriate. Therefore, the results of this study are presented in two different ways.

First, quantitative pre-post comparisons have been conducted, classifying women whose first survey was completed during the baseline phase as the pre-test group and those whose first survey was completed during the intervention phase as the post-test group. These results are summarised in the section entitled "Quantitative Results". Although not ideal, due to the small numbers, percentages have been presented in all the tables to enable easier comparisons between the groups. The percentages in each table throughout this section of the results may not add to 100% due to rounding.

Second, more qualitative, descriptive analyses were conducted to explore whether any changes occurred in the responses of those women who completed the survey more than once. These results are presented in the section entitled "Qualitative Results".



## Quantitative Results

### *Participants' Characteristics*

Table 1.1 summarises the demographic characteristics of the participating women. As shown, they were fairly evenly split between those aged less than and those aged more than 50 years. Slightly over three quarters were married or living with a partner; about half had a less than high school level of education; and almost half were in the workforce, with almost a third engaged in home duties.

**Table 1.1: Patients' demographic characteristics (%)**

	Baseline Phase (n=87)	Intervention Phase (n=34)	Total (n=121)
<b>Age</b>			
18 – 49 years	47	53	49
50+ years	53	47	51
Mean age (sd)	50.4 years (10.0)	48.7 years (9.6)	49.9 years (9.9)
Median age	50 years	47 years	50 years
<b>Current marital status</b>			
Married / living with partner	77	77	77
Divorced / separated / widowed / single	23	23	23
<b>Level of education</b>			
Didn't complete high school	49	53	50
Year 10 or equivalent	14	18	15
Year 12 or equivalent	13	9	12
University / trade / technical / other	24	20	23
<b>Usual employment situation</b>			
Employed full-time or part-time	44	46	44
Home duties	31	27	30
Student	2	6	3
Retired / unemployed / unable to work / other	23	21	23

Table 1.2 summarises the participating women's disease and past treatment characteristics. As shown, approximately half of the participating women were diagnosed with early-stage breast cancer, according to the Guidelines. However, for one in five participants, the information provided by the oncologists was insufficient to determine the stage of disease at diagnosis. Although a few women were attending for an initial visit with their oncologist, prior to starting treatment, the remaining women were reasonably split between those attending for treatment and those attending for follow-up only. There was a fairly even spread in the length of time since diagnosis. Most women had received surgical treatment, chemotherapy and radiotherapy, with a little over a quarter having had hormone therapy and very few having had ovarian treatment.

**Table 1.2: Patients' disease and treatment characteristics (%)**

	Baseline Phase (n=87)	Intervention Phase (n=34)	Total (n=121)
<b>Disease stage at diagnosis</b>			
Early ( <i>according to Guidelines</i> )	54	50	53
Advanced ( <i>according to Guidelines</i> )	31	21	28
Insufficient information to determine	15	29	19
<b>Reason for visiting oncology unit</b>			
Initial consultation with oncologist	2	12	5
Routine treatment session	56	41	52
Follow-up visit	42	47	43
<b>Time since breast cancer diagnosis</b>			
Less than 6 months	33	36	34
6 months – 2 years	28	21	26
More than 2 years	39	43	40
<b>Past treatments</b>			
Surgery (all types)	83	91	85
Chemotherapy	86	74	83
Hormone therapy	29	27	28
Radiotherapy	60	56	59
Ovarian treatment	2	0	2

### ***Level of Diagnosis in accordance with the Guidelines***

The Guidelines provide information on the most widely used information regarding how breast cancers are classified – the TNM clinical classification. TNM classifications are utilised to assign stage groupings (ie: Stage I, II, III or IV) to cases of breast cancer. These stage groupings are used to determine whether a woman's diagnosis is generally classified as "early" or "advanced" breast cancer. Oncologists' responses on the diagnostic and treatment information sheets, and their subsequent staging decisions, were compared against the criteria provided in the Guidelines – see Appendix 3 for a summary of these criteria. Table 1.3 summarises the level of agreement between the oncologists' staging decisions and the Guidelines during the baseline and intervention phases. The results appear somewhat mixed, with oncologists seeming more likely to stage patients earlier than the Guidelines during the intervention phase but more likely to assign patients the correct general classification (ie: early or advanced).

**Table 1.3:** The level of agreement between oncologists and the Guidelines regarding patients' stage groupings and general classifications, based on their TNM data (%)

	All Patients		Those With Diagnostic Forms	
	Baseline Phase (n=87)	Intervention Phase (n=34)	Baseline Phase (n=76)	Intervention Phase (n=26)
<b>Stage Grouping</b>				
Oncologist agreed with Guidelines	52	41	59	54
Oncologist earlier than Guidelines	8	18	9	23
Oncologist later than Guidelines	0	0	0	0
Insufficient information to determine	28	18	32	23
Diagnostic form not returned	13	23	--	--
<b>General Classification</b>				
Early, in agreement with Guidelines	37	44	42	58
Advanced, in agreement with Guidelines	16	21	18	27
Early, contrary to Guidelines	15	0	17	0
Advanced, contrary to Guidelines	5	4	5	4
Insufficient information to determine	15	9	17	11
Diagnostic form not returned	13	23	--	--

### ***Level of Treatment in accordance with the Guidelines***

In addition to explicit staging criteria, the Guidelines also indicate the appropriateness of chemotherapy, hormone therapy and ovarian treatments for patients depending on their menopausal status, node status, oestrogen receptor status and their age – see the flowchart in Appendix 3 for a summary of these criteria. Oncologists' responses on the diagnostic and treatment information sheets were compared against the recommendations provided in the Guidelines to determine the apparent appropriateness of patients' treatments. Table 1.4 summarises the level of agreement between patients' treatments and the Guidelines. As the Guidelines refer to women with early breast cancer, the numbers shown are smaller than in other tables, as they represent only these women. Although little change was seen in the proportion of patients treated in accordance with the Guidelines, the overall results were encouragingly high and it is probable that other factors, which we were unable to measure, play a role for many of those patients apparently not treated in accordance with the Guidelines.

**Table 1.4:** The level of agreement between patients' treatment regimens and the Guidelines, based on their menopausal, node and receptor status (%)

	Baseline Phase (n=47)	Intervention Phase (n=17)
<b>Chemotherapy</b>		
Correctly given	70	65
Correctly not given	6	18
Incorrectly given	6	6
Incorrectly not given	2	0
Insufficient information to determine	15	12
<b>Hormone Therapy</b>		
Correctly given	19	18
Correctly not given	34	41
Incorrectly given	21	23
Incorrectly not given	6	6
Insufficient information to determine	19	17
<b>Ovarian Treatment</b>		
Correctly given	2	0
Correctly not given	77	77
Incorrectly given	2	0
Incorrectly not given	0	0
Insufficient information to determine	19	23

### ***Women's Satisfaction with their Level of Involvement in Treatment Decisions***

The Guidelines state that all women should be encouraged to participate in decisions about their treatment but indicate that women have the right to delegate all the decision-making responsibility to their doctors. Table 1.5 suggests a drop in women's satisfaction with their level of involvement during the intervention phase, with a tendency for them to feel less involved than they would like to be.

**Table 1.5:** Women's satisfaction with their level of involvement in treatment decisions

	% women in treatment & F/U	
	Baseline Phase (n=83)	Intervention Phase (n=29)
Happy with level of involvement	92	79
Wanted to be MORE involved	7	21
Wanted to be LESS involved	0	0
Unsure	1	0

### ***The Adequacy and Appropriateness of Information Provided to Women***

The Guidelines also make recommendations about a wide range of information that should be available to women, including information about their diagnosis, potential treatments, the possible psychosocial impact of their illness and the availability of support services. The Guidelines also state that such information should be provided in a way and at a level that is appropriate for each patient. Therefore, this section reports on women's levels of satisfaction with both the amount and the nature of the information they received in relation to the range of issues raised within the Guidelines. Given the broad range of issues covered, not all questions were relevant for all patients. Therefore, the type and number of women answering each question is indicated within each table. The rationale for each issue is discussed and referenced in the baseline report (3).

Table 1.6 summarises women's retrospective assessments of the initial information they received about their treatment in the oncology unit they were visiting.

**Table 1.6: Women's satisfaction with the amount of initial information in this department**

	<b>Baseline Phase</b>	<b>Intervention Phase</b>
<b><i>Treatment patients only</i></b>	<b>(n=48)</b>	<b>(n=14)</b>
<b>Information about the aims of treatment</b>		
Happy with amount of information	90	93
Wanted MORE information	8	7
Wanted LESS information	2	0
Didn't get any information	0	0
<b><i>Follow-up patients only</i></b>	<b>(n=34)</b>	<b>(n=15)</b>
<b>Information about possible treatments</b>		
Happy with amount of information	85	80
Wanted MORE information	15	20
Wanted LESS information	0	0
Didn't get any information	0	0
<b>Information about the likely health outcomes</b>		
Happy with amount of information	88	73
Wanted MORE information	6	20
Wanted LESS information	3	0
Didn't get any information	3	7
<b>Information about the possible side effects</b>		
Happy with amount of information	76	80
Wanted MORE information	21	0
Wanted LESS information	0	0
Didn't get any information	3	20

	Baseline Phase	Intervention Phase
<b>Treatment &amp; follow-up patients</b>	(n=82)	(n=29)
<b>Information about the involved in treatment</b>		
Happy with amount of information	89	79
Wanted MORE information	9	14
Wanted LESS information	2	7
Didn't get any information	0	0
<b>Overall information level</b>		
Happy with amount of information	76	83
Wanted MORE information	23	14
Wanted LESS information	0	0
Didn't get any information	1	3

Table 1.7 summarises the satisfaction of women attending for follow-up visits regarding the amount of information received during their treatment about a range of support services.

**Table 1.7: Women's satisfaction with the amount of information received during treatment**

	Baseline Phase	Intervention Phase
<b>Follow-up patients only</b>	(n=34)	(n=15)
<b>Information about support groups</b>		
Happy with amount of information	59	60
Happy - didn't want any information	9	13
Wanted MORE or SOME information	32	20
<b>Information about social workers</b>		
Happy with information received	47	60
Happy - didn't want any information	26	27
Wanted MORE or SOME information	21	7
<b>Information about counsellor or psychologists</b>		
Happy with amount of information	38	53
Happy - didn't want any information	29	27
Wanted MORE or SOME information	29	20
<b>Information about breast cancer support services</b>		
Happy with amount of information	65	53
Happy - didn't want any information	3	20
Wanted MORE or SOME information	26	27
<b>Information about the goals of follow-up</b>		
Happy with amount of information	64	50
Happy - didn't want any information	3	19
Wanted MORE or SOME information	34	32

NB: totals may not add to 100% as some women could not recall their level of satisfaction

Table 1.8 summarises women's responses regarding their current levels of need for help with information about a range of issues.

**Table 1.8: Women's current levels of need for information**

	Baseline Phase	Intervention Phase
<b><i>Treatment patients only</i></b>	(n=48)	(n=14)
<b>Information about the pros &amp; cons of hormone therapies</b>		
GREAT or SOME need for information	50	58
No need - happy with current information	31	21
Issue not a concern	19	21
<b>Information about the pros &amp; cons of chemotherapy</b>		
GREAT or SOME need for information	36	57
No need - happy with current information	60	43
Issue not a concern	4	0
<b>Information about the pros &amp; cons of clinical trials</b>		
GREAT or SOME need for information	44	65
No need - happy with current information	35	14
Issue not a concern	21	21
<b><i>Follow-up patients only</i></b>	(n=34)	(n=16)
<b>Information about meaning for other women in family</b>		
GREAT or SOME need for information	59	75
No need - happy with current information	29	25
Issue not a concern	12	0
<b>Information about how often need check-ups</b>		
GREAT or SOME need for information	41	56
No need - happy with current information	56	44
Issue not a concern	3	0
<b>Information about whether future tests will be needed</b>		
GREAT or SOME need for information	74	81
No need - happy with current information	23	19
Issue not a concern	3	0
<b><i>Treatment &amp; follow-up patients</i></b>	(n=84)	(n=30)
<b>Information about the causes of breast cancer</b>		
GREAT or SOME need for information	41	47
No need - happy with current information	54	53
Issue not a concern	5	0
<b>Information about extent of breast cancer in community</b>		
GREAT or SOME need for information	38	47
No need - happy with current information	56	40
Issue not a concern	6	13

	Baseline Phase	Intervention Phase
<b>Treatment &amp; follow-up patients</b>	(n=84)	(n=30)
<b>Information about their type of breast cancer</b>		
GREAT or SOME need for information	52	56
No need - happy with current information	48	37
Issue not a concern	0	7
<b>Information about their chance of the cancer returning</b>		
GREAT or SOME need for information	74	73
No need - happy with current information	25	27
Issue not a concern	1	0
<b>Information about their chance of being cured</b>		
GREAT or SOME need for information	67	69
No need - happy with current information	32	30
Issue not a concern	1	1

The Guidelines also make some recommendations regarding communication between oncologists and patients' general practitioners and about the provision of information to women in the form of written treatment and follow-up plans and in the form of tape recordings of important parts of consultations. Table 1.9 summarises the oncologists' performance in relation to these issues.

**Table 1.9: Oncologists' use of other communication channels**

	Baseline Phase	Intervention Phase
<b>Treatment patients only</b>	(n=48)	(n=14)
<b>Got a written treatment plan?</b>		
Yes	15	29
No – and would like one	50	57
No – and don't want one	35	14
<b>Got a tape recording of consultation?</b>		
Yes	2	7
No – and would like one	27	36
No – and don't want one	71	57
<b>GP informed about treatment?</b>		
Yes	79	79
No or unsure – and don't want them informed	2	14
No or unsure – and would like one	17	7
Don't have regular GP	2	0



Table 1.10 summarises women's current need for help with a variety of issues.

**Table 1.10: Women's current levels of need for help**

	Baseline Phase	Intervention Phase
<b><i>Treatment patients only</i></b>	(n=48)	(n=14)
<b>With caring for children, elderly parents or spouse</b>		
Need LOTS or SOME help	19	21
No need - happy with current help	25	50
Issue not a concern	56	29
<b>With finding out about financial assistance available</b>		
Need LOTS or SOME help	43	50
No need - happy with current help	17	14
Issue not a concern	40	36
<b>With somewhere to stay near the hospital</b>		
Need LOTS or SOME help	0	0
No need - happy with current help	10	14
Issue not a concern	90	86
<b>With any special clothing, such as prostheses</b>		
Need LOTS or SOME help	6	8
No need - happy with current help	23	21
Issue not a concern	71	71
<b><i>Follow-up patients only</i></b>	(n=34)	(n=15)
<b>With finding out how to live a healthier lifestyle</b>		
Need LOTS or SOME help	29	53
No need - happy with current help	59	40
Issue not a concern	12	7
<b>With being able to talk to others about experiences</b>		
Need LOTS or SOME help	12	27
No need - happy with current help	73	53
Issue not a concern	15	20
<b>With any long term effects on family relationships</b>		
Need LOTS or SOME help	18	33
No need - happy with current help	59	47
Issue not a concern	23	20
<b><i>Treatment &amp; follow-up patients</i></b>	(n=82)	(n=30)
<b>With finding out how to meet a counsellor</b>		
Need LOTS or SOME help	15	20
No need - happy with current help	53	57
Issue not a concern	32	23

	Baseline Phase	Intervention Phase
<b>Treatment &amp; follow-up patients</b>	(n=82)	(n=30)
<b>With finding out how to join a support group</b>		
Need LOTS or SOME help	15	23
No need - happy with current help	51	50
Issue not a concern	34	27
<b>With finding out about the BCSS</b>		
Need LOTS or SOME help	19	24
No need - happy with current help	57	52
Issue not a concern	24	24
<b>With dealing with the possible long term effects for them</b>		
Need LOTS or SOME help	43	49
No need - happy with current help	48	48
Issue not a concern	9	3
<b>With feeling able to express their thoughts &amp; feelings</b>		
Need LOTS or SOME help	22	34
No need - happy with current help	66	59
Issue not a concern	12	7

### ***Appropriateness of patient follow-up care***

The Guidelines also recommends a minimal follow-up schedule that should be observed for 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 1.11 provides information on how often the patients attending for follow-up had presented for a follow-up consultation with a medical oncologist.

**Table 1.11: The proportion of women who had a follow-up consultation and length of time**

To come – but was 97% ok at baseline – so little change expected.

### **Qualitative Results**

To come – will look at what changes, if any have occurred in the responses of those people having completed the survey more than once.

## **Acceptability of the Intervention**

### ***Acceptability to patients***

To come

### ***Acceptability to hospital staff***

To come

## **Discussion**

To come – when all results explored in more depth.

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3. Rankin N, Newell S, Sanson-Fisher RW, Girgis A. Assessing the Effectiveness of Computerised Dissemination of the “NHMRC Clinical Guidelines for the Management of Early Breast Cancer”: Baseline Report. Report prepared for the NHMRC National Breast Cancer Centre, July 1998.

## Appendix 1: Diagnostic and Treatment Information Form



### *Medical Oncologists' Dissemination Trial*



#### 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 |      |

<b>Treatment History/Status</b>			
	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:

<b>TNM Classification - please circle</b>														
<b>T Categories</b>	TX	T0	Tis	T1	T1a	T1b	T1c	T2	T3	T4	T4a	T4b	T4c	T4d
<b>N Categories</b>	NX	N0	N1	N2	N3									
<b>M Categories</b>	MX	M0	M1											
<b>Stage Groupings -</b>														
please circle	Stage 0	Stage I	Stage IIA	Stage IIB	Stage IIIA	Stage IIIB	Stage IV							

## Appendix 2: Computerised Feedback to Oncologists



### *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

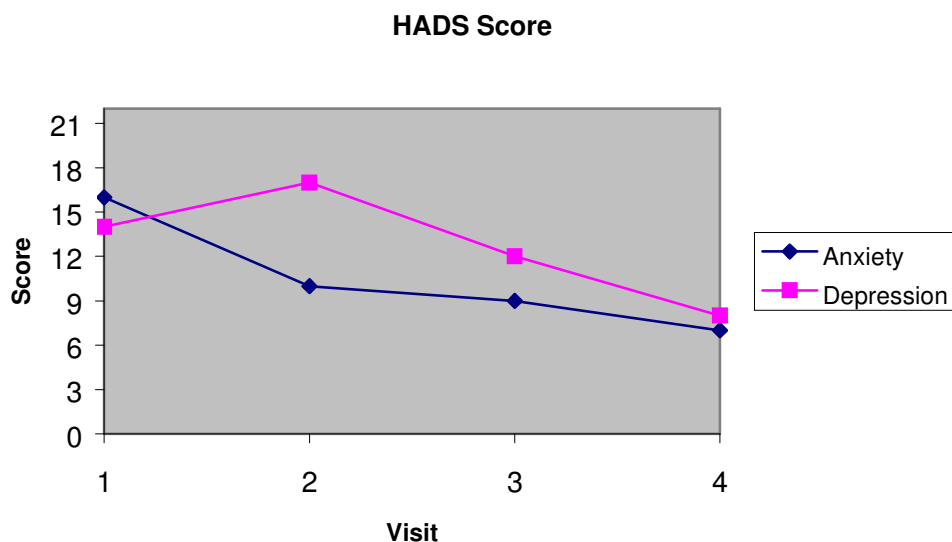
## PHYSICAL SYMPTOMS

SYMPTOM	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 & DEPRESSION LEVELS

Key: (0-7: low level; 8-10 borderline level; 11-21 clinical level)



## Appendix 3: Diagnostic & Treatment 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	yes no can't tell
General classification:	early advanced	missing		early advanced	yes no can't tell
		missing		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	N1	M0
	T1	N1	M0
	T2	N0	M0
Stage IIB	T2	N1	M0
	T3	N0	M0
Stage IIIA	T0	N2	M0
	T1	N2	M0
	T2	N2	M0
	T3	N1, N2	M0
Stage IIIB	T4	Any N	M0
	Any T	N3	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

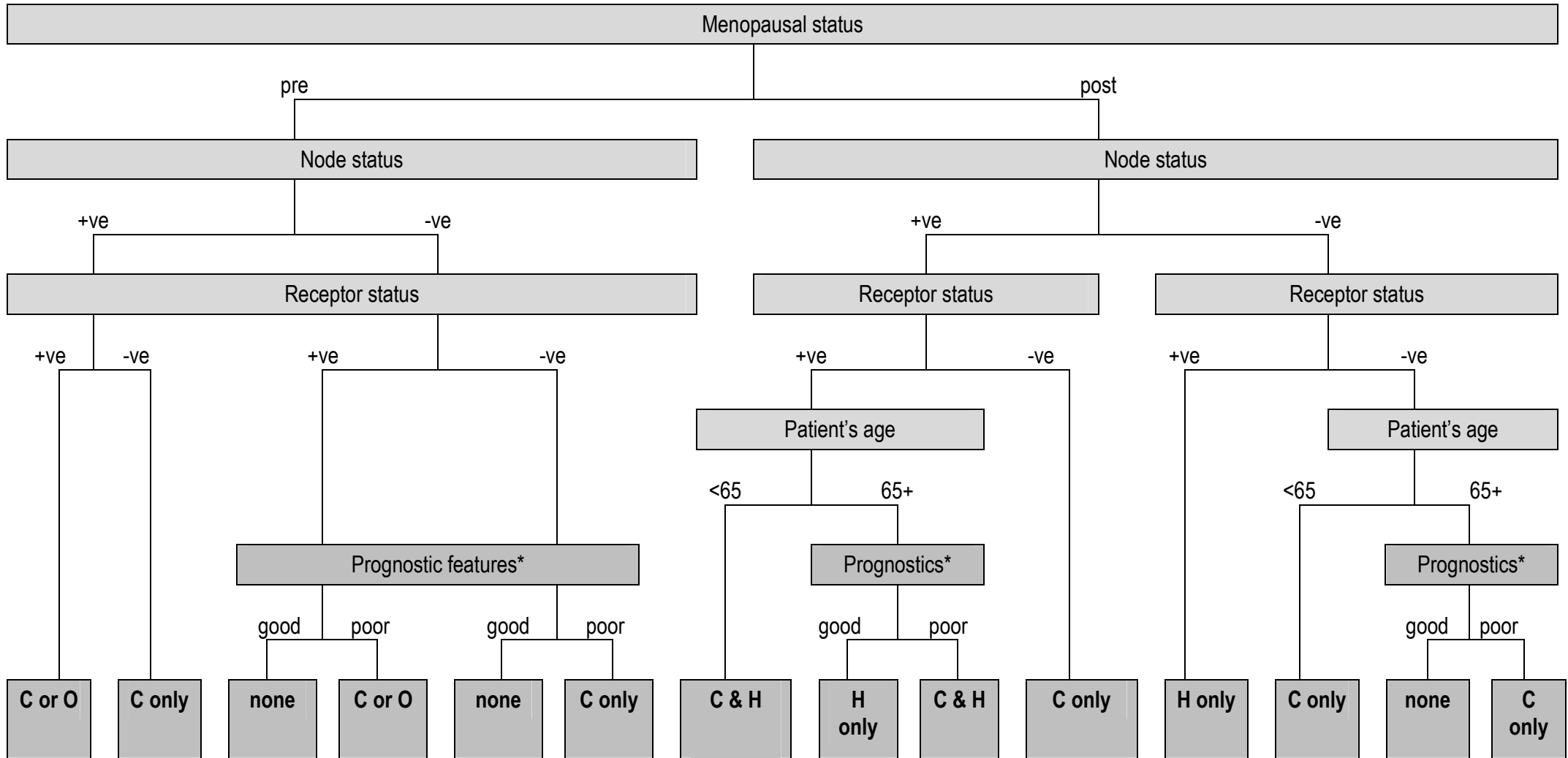
**Medical Oncologists' Dissemination Trial: Treatment Feedback**  
***(for patients with early breast cancer only)***

On the last Patient Diagnosis Record Sheet, the following was noted about this patient's treatment history:					
<b>Menopausal status:</b>	pre	peri	post	missing	
<b>Node status:</b>	+ve	-ve	unclear	missing	
<b>Receptor status:</b>	+ve	-ve	unclear	missing	
<b>Age:</b>	< 65 years		65+ years		
<b>Systemic treatments:</b>	<b>chemotherapy:</b>				
	none	CMF(P)	doxorubicin & cyclophosphamide	other	missing
	<b>hormone therapy:</b>				
	none	tamoxifen	other	missing	
	<b>ovarian therapy:</b>				
	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<sup>1</sup>



**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