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TITLE: Development and Evaluation of Computer-Based Versions of  
the Decision Board for Early Breast Cancer

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## Introduction

Women with breast cancer have increasingly indicated a desire for more information about their disease and need to be involved in decisions about their care. The main objective of the study is to further enhance information transfer between the doctor and patient giving women with early stage breast cancer an opportunity to more fully participate in treatment decision making. In this study, computer-based versions of decision aids (called Decision Boards) have been developed for three decision-making scenarios: 1) surgical treatment of early breast cancer, 2) chemotherapy for node-negative breast cancer, and 3) chemotherapy for node-positive breast cancer. The computer versions are based on previous Decision Boards and have been developed through an iterative process with focus groups of patients and clinicians. Feasibility testing confirmed good overall patient comprehension and acceptability. The computer versions will now be compared with standard versions in a randomized trial. We hypothesize that the many advantages of computer-based versions will result in improved patient understanding as well as patient and physician satisfaction.

## Body

Progress made since our last review towards meeting objectives date is outlined below. Standard instruments have been updated and we have developed computer-based versions of all three boards (surgery Decision Board and the chemotherapy Boards for node-positive and node negative breast cancer). Currently we are in the process of preparing for initiating the randomized control trial.

### **Task 1: Development of Computer-Based Version of Decision Boards and Updating the Standard Versions of the Decision Board Currently Used at the HRCC and Outlying Communities (Months 1 – 12)**

- **Perform a systematic review of the three treatment options (months 1)**

Completed.

- **Conduct focus groups (months 1-3)**

Completed.

- **Development of computerized versions of Decision Boards**

As indicated in last year's report, our intention was first to develop and test the prototype of the surgery Decision Board and then to develop the remaining two instruments.

Surgery Decision Board – Development of the computer-based surgery decision board was described in last year's report. A take-home (see Appendix A) has been developed and tested with patients. Minor modifications have been incorporated reflecting the findings of our field testing results. Specifically, an opening screen was added to the computer program allowing the surgeon to choose either the presentation that includes or the presentation that omits the discussion of axillary

node dissection depending on the patient's age and co-morbidity.

Computerized Chemotherapy Decision Boards – As with the surgery decision board, programs for the computerized chemotherapy decision boards were written using the Pascal-based Borland Delphi Version 3. This object-oriented programming environment has permitted us to retain the positive attributes of the standard versions while allowing us to add features unique to the computer interface. Through the use of active components in the visual display (i.e., buttons, tabs and hypertext links), the user is given access to progressive depths of information on selected topics. Microsoft "Wizard"-like sequences grant the user full navigational control. These programs were designed for a Windows-based platform and are easily accessed through a native standalone executable program file.

The computer versions of the chemotherapy decision boards were modeled on the standard versions. To ensure the information presented in the standard versions of the chemotherapy decision boards is specific to a patient's diagnostic features, both the node negative and the node positive standard boards were devised with several risk scenarios. Each risk scenario presents information on the treatment options, risk of side effects and risk of recurrence specific to a particular risk category. Consequently with the standard decision boards, for each patient, the appropriate scenario had to be sorted and arranged prior to presenting the information to the patient. To overcome this administrative burden, the opening screen in the computer program requests information specific to the patient's diagnostic features including type of surgery (mastectomy or lumpectomy), menopausal status, nodal status, tumour size, tumour grade, estrogen receptor status and the presence or absence of lymphovascular invasion. Upon entering the required information on the first screen, the program links into the version which displays the appropriate treatment options and estimates of risk of recurrence based on the patient's diagnostic features.

As in the standard versions, the computerized boards consist of panels of information describing the

patient's chemotherapy treatment options, side effects associated with the treatment options and risk of recurrence. With the computerized node negative decision board, the first decision centers on the patient's preference for whether or not to take chemotherapy. After her diagnostic features are entered in the opening screen, the program links into a screen that depicts two scenarios: no chemotherapy and chemotherapy. The "no chemotherapy" scenario describes treatment and follow-up if she chooses not to take chemotherapy while the "chemotherapy" scenario gives a general overview of how chemotherapy is given, a list of the general side effects and follow-up if she choose to take chemotherapy. If the patient wishes to consider chemotherapy, the oncologist clicks on a box which links into an overview panel laid out as a grid that lists the appropriate chemotherapy options (CMF and AC) down the left side and the titles "Treatment Option", "Side Effects" and "Outcomes" across the top. Across the bottom of the screen, additional panels provide an introduction, a brief discussion of the use of the decision board and a graph depicting the risk of experiencing menopausal for various treatment combinations. To present the information to the patient, the oncologist clicks on a box in the grid that corresponds to information he/she wishes to present. The panel opens to reveal the information. After the information has been reviewed with the patient, the panel is exited and a brief point form description of the information is displayed in the grid.

In the node negative decision board, for each of the two treatment options (CMF and AC), information is presented on the treatment regimens, associated side effects and the risk of recurrence verses the chance of remaining cancer free. Under the heading "Treatment Option", a calendar depicts the drug treatment schedule, the number of drugs administered, the mode of administration and the length of the treatment (see Appendix B). Under the heading "Side effects", a graph depicting the chance of experiencing side effects that differ between the two types of chemotherapy is shown for each treatment option. In the last column under "Outcome", probability wheels are used to depict the risk of cancer returning and the chance of remaining cancer free for

each treatment regimen in the seven years after diagnosis. Clicking on the probability wheel displays information on what it may be like for the patient if she is cancer free or if she experiences a recurrence.

In the computer version of the node positive decision board, after entering information on the patient's diagnostic features, the program links directly into a grid similar to that described above. Four treatment options appear along the left side of the grid: no treatment (provided for comparison purposes), CMF, AC, CEF (see Appendix C). Under "Side Effects", because of the increased risk of serious sequelae with some regimens, an additional graph illustrates the risk of experiencing side effects that are rare but potentially life-threatening, e.g., risk of severe infection, leukemia and heart disease, for each treatment option (see Appendix D). The last column includes a probability wheel for each of the four treatment options depicting the risk of a recurrence versus the chance of remaining cancer free in the five years after diagnosis. Included in the panels along the bottom of the screen is a box that links into a general discussion of chemotherapy and a list of side effects common to all chemotherapy regimens along with the introduction, description of the decision board and risk of experiencing menopause.

As with the surgery decision board, for each of the chemotherapy boards, the patient is given a customized booklet of the information she discussed with her oncologist for her to take home and review.

**Field testing of instruments on 9-15 clinicians and 48 patients not previously involved in the developmental state to determine if the instruments are acceptable and non-threatening to patients and physicians at the decision point (months 6 – 12)**

Surgery Decision Board – Field testing of the surgery instrument has been completed at five surgical outpatient clinics in the community. The instrument was tested on 20 patients at the

decision point. Based on the feedback, the instrument has been modified accordingly as we prepare to enter the randomized trial.

Our results showed that 98% of patients agreed to participate in the pilot study. All patients who agreed to participate in the study completed the interview. The average score on the comprehension test (40 True/False items) was 78.3% which was felt to be adequate.

In terms of acceptability, patients were asked how understandable was the information presented in the decision board, whether the decision board helped them to decide on a treatment, helped them ask questions and would they recommend it to other patients. All patients found the Board to be very easy (70%) or easy (30%) to understand. All patients indicated that the Board was either very helpful (85%) or somewhat helpful (15%). Seventy-five percent felt that the Board definitely helped (50%) or helped (25%) them to think of questions to ask their surgeon. Two patients (10%) indicated that the Decision Board had answered all their questions and therefore they did not have any questions to ask. All patients said they would recommend the decision board to other patients. When asked how strongly they either agreed or disagreed with the statement "I am satisfied with the overall decision making process," 65% strongly agreed and 30% agreed with the statement. Only one patient felt equivocal as she would have liked her surgeon to play a stronger role in recommending a treatment.

In terms of surgeons' satisfaction with the computerized instrument, of the five surgeons who participated in the pilot study, all indicated that the Decision Board definitely helped (100%) in presenting the treatment options to the patient. Furthermore, all indicated that it was either easy (73%) or relatively easy (27%) for them to discuss the information on the Decision Board with the patient and simultaneously navigate through the program.

Node-Negative Chemotherapy Decision Board – As indicated in last year's report, our intention

was to begin field testing the computer version after completing accrual for the ongoing RCT of the standard node negative board. Accrual for the RCT of the node negative board comparing the medical consultation plus the decision board versus the medical consultation alone was recently completed. In total, 177 patients were randomized from five clinical centres. The analysis has been completed and the results, which are quite promising, will be submitted for publication. The computer version of the node negative instrument is now being pretested in the clinic.

Node-Positive Chemotherapy Decision Board – Based on the literature review (see last year's reports) and information gathered at the focus groups held with patients and medical oncologists, the standard version of the node-positive decision board underwent extensive revisions. At the request of the oncologists, calendars showing the treatment regimen for each chemotherapy option were included. In addition, extensive testing was conducted with patients to determine which graphical layout most preferred by patients for presenting information on the outcomes (risk of recurrence and/or chance of survival). We therefore elected to pilot test the revised standard version of this board with 30 patients and their oncologists at the decision point. Thirty patients were approached about the study and agreed to participate in the pilot testing. All patients found the decision board either very easy (73%) or easy (27%) to understand. All patients stated that the Decision Board helped them to decide which treatment option they preferred. All patients indicated they would recommend the decision board to other patients. When asked how strongly they either agreed or disagreed with the statement "I am satisfied with the overall decision making process," all indicated they agreed with the statement (70% strongly agreed and 30% agreed).

Eight medical oncologists participated in the pilot study. With respect to the acceptability of the board, in 97% of patient encounters, medical oncologists felt that using the Decision Board either definitely helped (63%) or helped (33%) them present the patient with information on her treatment options.

Field testing is being conducted on the node-positive instrument.

### **Task 2: Start-up of the RCT Study (Months 13 – 16)**

- **Development of operations manuals, revision of data forms, training of clinicians to use the computer-based versions**

Surgery decision board stratum – An operations manual and data forms have been drafted. Data forms were revised to reflect changes identified in the field testing process. Surgeons have been trained on the use of the standard and computerized instruments and their staff has been instructed on obtaining informed consent as well as forwarding appropriate documentation to our office to allow us to proceed with data collection. Ethics board approval has been obtained.

Chemotherapy decision boards stratum – The RCT will begin following completion of field testing.

- **Locate computers and printers in designated study sites**

Computers have been placed in the offices of five community surgeons.

### **Task 3: Patient Recruitment and Data Collection (Months 16 - 39)**

The randomized control trial of the surgery decision board is scheduled to begin in January. The following tasks will be addressed at that time.

- **Patient recruitment into the study for a total accrual of 180 subjects**
- **Telephone interviews will be conducted for subjects recruited within the community surgeons' offices**
- **Patient self-administered questionnaires provided to eligible study patients attending the**

## **cancer clinic**

- **On-going data entry of data forms and questionnaires**

Significant progress has been made in reaching our first and second year milestones as outlined in our Statement of Work. The study is remains slightly behind schedule (approximately six months) due to a number of events. As indicated in last year's report, recruitment of the research coordinator was more protracted than anticipated and it was deemed appropriate that the instruments be developed in a sequential fashion rather than concurrently. New information about the effectiveness of different types of chemotherapy, Adriamycin and Cyclophosphamide (AC) for node negative disease and Cyclophosphamide, Epirubicin and 5-Fluoruracil (CEF) for node positive disease resulted in major changes to the standard versions of the chemotherapy decision boards. These required some field testing. An ongoing randomized trial evaluating the standard node-negative chemotherapy instrument has delayed field testing of the computerized version. Enrolment for the randomized trial evaluating the standard node-negative chemotherapy instrument closed. This summer, field testing for the computer version of the surgery decision board was completed and field testing of the computer version of the node negative and node positive instruments are almost completed. Our plan is to begin the RCT of the computer versus standard versions in the spring.

## Key Research Accomplishments

### Year 1

- Completed a review of the literature and updated the standard version of the surgery Decision Board
- Completed a review of the literature and updated the standard version of the node-negative Decision Board
- Completed a review of the literature and updated the standard version of node-positive Decision Board
- Developed the computerized version of the surgery Decision Board

### Year 2

- Completed field testing of the computerized version of surgery Decision Board
- Developed prototype of the computerized version of the node-negative Decision Board
- Completed field testing of the standard version of the node positive Decision Board
- Developed a prototype of the computerized version of the node-positive Decision Board
- Field testing of the computerized version of the node-positive Decision Board
- Field testing of the computerized version of the node-negative Decision Board

## Reportable Outcomes

### Surgical Decision Board

- Standard version (updated)
- Computerized version (developed)
- Field testing
- Analysis of field testing phase

### Node-Negative Decision Board

- Standard version (updated)
- Computerized version (developed)
- Field testing

### Node-Positive Decision Board

- Standard version (updated) and pilot tested
- Computerized version (developed)
- Field testing

## **PUBLICATIONS**

Charles C, Gafni A, Whelan T. International Conference on Treatment Decision-Making in the Clinical Encounter. *Health Expectations*, 2000; 3:1-5.

Charles C, Gafni A, Whelan T. How to improve communication between doctors and patients. *British Medical Journal*, 2000; 230:1220-1221.

Whelan T, Gafni A, Charles C, Levine M. Lessons learned from the Decision Board: A unique and evolving decision aid. *Health Expectations*, 1999; 3:69-76.

Charles C, Whelan T, Gafni A. What do we mean by partnership in making decisions about treatment. *British Medical Journal*, 1999; 319: 780-782.

Whelan T, Levine M, Gafni A, Sanders K, Willan A, Mirsky D, Schnider D, McCready D, Reid S, Kobylecky A, Reed K. Mastectomy or lumpectomy? Helping women make informed choices. *Journal of Clinical Oncology*, 1999; 17:1727-1735.

Irwin E, Arnold A, Whelan TJ, Reyno LM, Cranton P. Offering a choice between two adjuvant chemotherapy regimens: A pilot study to develop a decision aid for women with breast cancer. *Patient Education and Counselling* 1999; 37:283-291.

## PRESENTATIONS

Whelan, Sebaldt, Gafni, Levine, Bodendorfer, Tozer, Sanders, Reid. Computer-Based Versions of the Decision Board: An interactive Decision Aid for Early Breast Cancer. Presented at the Era of Hope Meeting, Department of Defense Breast Cancer Research Program, US Army Medical Research and Materiel Command, Atlanta, Georgia, June 8-12, 2000.

Whelan T, Levine M, Gafni A, Sanders K, Willan A, Mirsky D, Schnider D, McCready D, Reid S, Kobylecky A, Reed K. Mastectomy or lumpectomy? Helping women make informed choices. The Canadian Breast Cancer Research Initiative (CBCRI) "Reasons for Hope" National Scientific Conference, Toronto, June 17-19, 1999.

Whelan T. The Use of Decision Boards in Oncology. The 12<sup>th</sup> Centre for Health Economics and Policy Analysis Conference (CHEPA) "Treatment Decision-Making in the Clinical Encounter", McMaster University, Hamilton, ON, May 19-21, 1999.

Whelan, T. Decision Aids in Oncology. Cancer Care Quality of Life and Outcomes Symposium, Chicago, IL November 13-15, 1998.


## Conclusions

Conducting field tests on our decision boards has ensured that our instruments meet the needs of both the patient who wants to understand her disease and the appropriate treatment options and the clinician who wants to help the patient participate in the treatment decision making process. Field testing results of the decision boards have confirmed that they are easy for the patient to understand, easy for the clinicians to use and acceptable to both. Many patients have keenly volunteered for the field testing phase of these instruments, voiced their support for the direction of this research and praised their clinicians for involving them in the decision making process. The iterative process used for revising and testing the standard node positive chemotherapy decision board has created a sense of ownership among the oncologists involved in the development process. At this point, we look forward to beginning the randomized control trial of comparing the standard versions to the computerized versions of the decision boards.

## Appendices

- Appendix A: Computerized Surgery Decision Board For Patients Considering Surgical Treatment Options for Breast Cancer: Take Home Copy for Patients
- Appendix B: Computerized Node-Positive Decision Board – CMF Description of Choice
- Appendix C: Computerized Node Positive Decision Board – Overview Panel
- Appendix D: Computerized Node-Positive Chemotherapy Board – AC Side Effects Panel

Appendix A: Computerized Surgery Decision Board For Patients  
Considering Surgical Treatment Options for Breast Cancer:  
Take Home Copy for Patients



*Computerized Surgery Decision Board  
For Patients Considering  
Surgical Treatment Options  
for Breast Cancer*

Take Home Copy  
for Patients





## About the Decision Board

- ◆ To present the information in a more detailed way, a computer-based Decision Board was used. Using this Board, the following were presented:
  - ◆ a description of your two choices,
  - ◆ the side effects of each choice, and
  - ◆ the results of each choice for your breast and for survival.
- ◆ Below is an illustration of the covered Decision Board. The following pages show the panels section by section.
- ◆ It is important to remember that there is no right or wrong decision. We want you to make the decision that is best for you personally.
- ◆ We will provide you with much information today. Take as much time as you need to make your decision. *If anything is unclear, please call our office.*
- ◆ This take-home copy is intended for you to take the information home with you, for you to think about what choice is best for you and to help you explain the treatments to others if you like. You can make your decision over the next couple of days.

Mastectomy	Description of Choice	Side Effects of Choice	Results of Choice for Breast	Results of Choice for Survival
	Description	Description	Description	Description
Lumpectomy Plus Radiation	Description	Description	Description	Description
General Info	Introduction		About the Decision Board	Summary



## Introduction

- ◆ Breast cancer may be treated in a variety of ways including surgery, radiation, chemotherapy and hormonal therapy.
- ◆ The first step in the treatment of breast cancer is to remove the cancer by surgery.
- ◆ Today we discussed your two choices for surgical treatment. This is not a decision that I, as your surgeon, can make alone. We feel it is important for you to understand a little bit about breast cancer so that you can take part in deciding what is best for you.
- ◆ Two types of surgery are possible:
  - ◆ One is removal of the breast, called a mastectomy;
  - ◆ The second is removal of the lump, called a lumpectomy.

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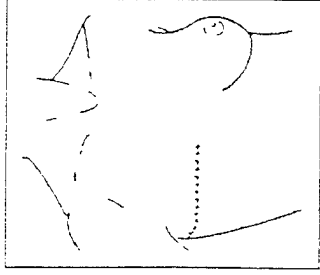
## Introduction, con't

- ◆ Since the early 1980's the results of medical studies have shown that the two treatments are the same for survival. In other words, one treatment is not better than the other for improving your chances of surviving cancer.
- ◆ The two treatments do differ, however.
  - ◆ Mastectomy results in the loss of your breast, and usually no radiation is required.
  - ◆ Lumpectomy, on the other hand, involves removal of the part of the breast that contains cancer, and in addition, radiation is part of the treatment.
- ◆ Both of these treatments also include an axillary node dissection.
  - ◆ Some nodes or glands under the arm are removed at the time of surgery.
  - ◆ This is done to see if the cancer has spread to these nodes.
- ◆ If cancer spreads to these nodes, there is a higher chance that the cancer may spread to other parts of the body.
- ◆ This is important information for you and your doctor to help decide if other treatments, such as hormonal therapy or chemotherapy, are necessary.



Description of Choice	Side Effects of Choice	Results of Choice for Breast	Results of Choice for Survival
<b>Mastectomy</b>			
<b>Mastectomy Plus Radiation</b>			
<b>Lumpectomy Plus Radiation</b>			
<b>General Info</b>			
<b>MASTECTOMY</b> <i>Description</i>			
MASTECTOMY <i>Surgical Removal of the Breast</i> <ul style="list-style-type: none"> <li>• The entire breast will be removed</li> <li>• Some of the lymph nodes under your arm will be removed</li> <li>• A drain is inserted near the scar under the arm for 5 -- 10 days to remove excess fluid</li> <li>• You will come to the hospital on the day of your surgery. You will spend one night in hospital and go home the next day.</li> <li>• After surgery, you may be referred to the Cancer Centre for consideration of other treatments (hormonal therapy or chemotherapy).</li> <li>• Radiation is not usually necessary</li> </ul>			

Mastectomy	Description of Choice	Side Effects of Choice	Results of Choice for Breast	Results of Choice for Survival
<p>Lumpectomy Plus Radiation</p> <p>General Info</p>	<p>MASTECTOMY</p> <p>OFTEN</p> <ul style="list-style-type: none"> <li>• Numbness and discomfort under the arm where the nerves were cut.</li> <li>• Pain, discomfort or numbness of the chest</li> </ul> <p>SOMETIMES</p> <ul style="list-style-type: none"> <li>• Stiffness of the shoulder.</li> </ul> <p>RARELY</p> <ul style="list-style-type: none"> <li>• Infection.</li> <li>• Swelling of the arm.</li> </ul>	<p>MASTECTOMY</p> <p>Side Effects</p>		

Mastectomy	Description of Choice	Side Effects of Choice	Results of Choice for Breast	Results of Choice for Survival
Lumpectomy Plus Radiation	<p><b>MASTECTOMY</b> <i>Results for Breast</i></p> <p><b>MASTECTOMY</b></p> <ul style="list-style-type: none"> <li>You are left with a healed scar across your chest</li> <li>Some women may be upset by the loss of their breast.</li> <li>A breast prosthesis or breast form can be fitted.</li> <li>The breast can be reconstructed using plastic surgery.</li> <li>Cancer may come back on the chest. About 5 to 10 out of 100 women will experience this in the next 10 years.</li> <li>Cancer that comes back on the chest is usually treated with surgery, radiation or both.</li> </ul>			
General Info				

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Description of Choice	Side Effects of Choice	Results of Choice for Breast	Results of Choice for Survival
<b>Mastectomy</b>			
<b>Lumpectomy Plus Radiation</b>			
<b>General Info</b>			

**MASTECTOMY**  
*Results for Survival*

Your chance of surviving cancer is the SAME as with

Lumpectomy plus Radiation.

22  
13

Mastectomy	Description of Choice	Side Effects of Choice	Results of Choice for Breast	Results of Choice for Survival
			<b>LUMPECTOMY plus RADIATION</b> <i>Description</i>	
<b>Lumpectomy Plus Radiation</b>	<b>LUMPECTOMY: Surgical Removal of the Lump</b>			
<b>General Info</b>				

**LUMPECTOMY: Surgical Removal of the Lump**

- Only the cancerous lump and some surrounding tissue will be removed.
- Some lymph nodes under your arm will be removed.
- A drain is inserted near the scar under the arm for 5-10 days to remove excess fluid.
- You will come to the hospital on the day of your surgery. You will spend one night in hospital and go home the next day.
- In about 1 out of 10 women, all the cancer in the breast may not be removed and further surgery may be necessary.
- After the breast has healed, you will be referred to the Cancer Centre for radiation therapy.

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**PLUS**

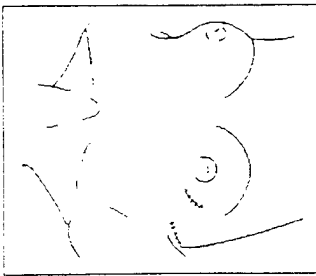
Description of Choice	Side Effects of Choice	Results of Choice for Breast	Results of Choice for Survival
Mastectomy	<b>LUMPECTOMY plus RADIATION</b> <i>Description</i>		
Lumpectomy Plus Radiation	<p><b>RADIATION: X-Ray Treatment</b></p> <ul style="list-style-type: none"> <li>• You will need to meet with a radiation oncologist at the Cancer Centre to plan radiation treatments.</li> <li>• The time between your surgery and the beginning of your radiation treatments may be 6 to 12 weeks.</li> <li>• Your treatments will be daily for 3 to 5 weeks, excluding weekends and holidays.</li> <li>• Each visit lasts about 30 to 45 minutes.</li> <li>• Other treatments (hormonal therapy or chemotherapy) may be considered.</li> <li>• If you are treated with chemotherapy, your radiation will begin when the chemotherapy is finished.</li> </ul>		
General Info			

Mastectomy	Description of Choice	Side Effects of Choice	Results of Choice for Breast	Results of Choice for Survival
	<p><b>LUMPECTOMY plus RADIATION</b>  <i>Side Effects</i></p>			
<p><b>Lumpctomy plus Radiation</b></p>	<p><b>LUMPECTOMY</b>  <i>OFTEN</i></p> <ul style="list-style-type: none"> <li>• Numbness and discomfort under the arm where the nerves were cut.</li> <li>• Pain or discomfort of the breast.</li> </ul> <p><i>SOMETIMES</i></p> <ul style="list-style-type: none"> <li>• Stiffness of the shoulder.</li> </ul> <p><i>RARELY</i></p> <ul style="list-style-type: none"> <li>• Infection.</li> <li>• Swelling of the arm.</li> </ul>			
<p><b>General Info</b></p>				<p><i>continued...</i></p>

## PLUS

Description of Choice	Side Effects of Choice	Results of Choice for Breast	Results of Choice for Survival
<b>Mastectomy</b>	<b>LUMPECTOMY plus RADIATION</b> <i>Side Effects</i>		
	<p><b>RADIATION</b></p> <p><i>OFTEN</i></p> <ul style="list-style-type: none"> <li>• Redness of the skin like a sunburn.</li> </ul>		
<b>Lumpectomy Plus Radiation</b>	<p><i>SOMETIMES</i></p> <ul style="list-style-type: none"> <li>• Increased tiredness.</li> <li>• Tanning of the skin.</li> <li>• Slight increase in firmness of the breast.</li> </ul>		
<b>General Info</b>	<p><i>RARELY</i></p> <ul style="list-style-type: none"> <li>• Blood vessels may become visible on small areas of the skin.</li> <li>• Other side effects occur very rarely (e.g., pneumonitis -- a temporary cough and shortness of breath).</li> </ul>		

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Mastectomy	Description of Choice	Side Effects of Choice	Results of Choice for Breast	Results of Choice for Survival
<p><b>Lumpectomy Plus Radiation</b></p>	<p><b>LUMPECTOMY plus RADIATION</b> <i>Results for Breast</i></p>	<p><b>LUMPECTOMY plus RADIATION</b></p> <ul style="list-style-type: none"> <li>You are left with 2 healed scars: one on the breast and one under the arm.</li> <li>There may be some indentation where the lump was removed or thickening of the breast tissue.</li> <li>Some women may be upset by the appearance of the breast, but most (8 out of 10 women) are comfortable with the way their breast looks.</li> <li>Cancer may come back on the chest. About 5 to 10 out of 100 women will experience this in the next 10 years.</li> <li>Cancer that comes back in the breast is usually removed by further surgery (lumpectomy or mastectomy). Radiation cannot be given again to the same breast</li> </ul>		
<p><b>General Info</b></p>				

Mastectomy	Description of Choice	Side Effects of Choice	Results of Choice for Breast	Results of Choice for Survival
Lumpectomy Plus Radiation	<b>LUMPECTOMY plus RADIATION</b> <i>Results for Survival</i>		Your chance of surviving cancer is the <b>SAME</b> as with Mastectomy.	
General Info				

	Description of Choice	Side Effects of Choice	Results of Choice for Breast	Results of Choice for Survival
<b>Mastectomy</b>	<ul style="list-style-type: none"> <li>Entire breast is removed</li> <li>Radiation is not usually necessary</li> </ul>	<ul style="list-style-type: none"> <li>Side effects of surgery e.g. numbness, pain</li> </ul>	<ul style="list-style-type: none"> <li>Loss of the breast</li> <li>Occasionally, cancer will come back</li> </ul>	<ul style="list-style-type: none"> <li>Your chance of surviving cancer is the same as with Lumpectomy plus Radiation</li> </ul>
<b>Lumpectomy Plus Radiation</b>	<ul style="list-style-type: none"> <li>Only the cancerous lump is removed</li> <li>3 to 5 weeks of radiation treatments</li> </ul>	<ul style="list-style-type: none"> <li>Side effects of surgery e.g. numbness, pain</li> <li>Side effects of radiation e.g. redness of the skin</li> </ul>	<ul style="list-style-type: none"> <li>Scar on the breast</li> <li>Occasionally, cancer will come back</li> </ul>	<ul style="list-style-type: none"> <li>Your chance of surviving cancer is the same as with Mastectomy</li> </ul>
<b>General Info</b>	<p>Introduction</p> <ul style="list-style-type: none"> <li>Other treatments, such as hormonal therapy or chemotherapy may be necessary</li> </ul>	<p>The Decision Board</p> <ul style="list-style-type: none"> <li>To provide information and to help you ask questions</li> </ul>	<p>Summary</p> <ul style="list-style-type: none"> <li>Some points to consider when making your choice</li> </ul>	

## SUMMARY

- ✦ We have discussed your choices for surgery, what the options entail, the side effects and the possible outcomes.
- ✦ Please review this take-home version carefully to make sure that you understand what is available.
- ✦ Remember, the chances of survival are the same for both choices. In deciding between the two options, think about the issues which will affect your day-to-day life.
- ✦ You may want to consider some of the following:
  - ✦ How will the results of your treatment choice affect your daily activities, for example, the way you dress or the style of clothing you like to wear?
  - ✦ How will the results of your treatment choice affect the way you feel about yourself, your body and your sexuality?
  - ✦ How will the results of your treatment choice affect your relationships with others?
  - ✦ Will the treatment you choose be inconvenient for you? Consider the length of the treatment and the need to travel to the Cancer Centre. In many areas, Cancer Society volunteers are available to drive patients to their appointments at the Cancer Centre.



Mastectomy	Description of Choice	Side Effects of Choice	Results of Choice for Breast	Results of Choice for Survival
Lumpectomy Plus Radiation	<p align="center"><b>MASTECTOMY</b> <i>Results for Breast</i></p> <p><i>Breast Reconstruction</i></p> <ul style="list-style-type: none"> <li>• Following mastectomy, the breast can be reconstructed using plastic surgery performed by a plastic surgeon.</li> <li>• You will need to meet with the plastic surgeon to discuss the procedure in more detail.</li> <li>• Breast reconstruction is performed in one of two ways:               <ul style="list-style-type: none"> <li>• Using a saline (salt-water) filled implant inserted under the skin, or</li> <li>• With more extensive surgery using your own tissue (often taken from your abdomen)</li> </ul> </li> <li>• Reconstruction of the breast can be performed simultaneously with mastectomy, or the procedure can be done at a later time.</li> <li>• With current surgical techniques, the reconstructed breast often looks similar to your normal breast.</li> </ul>			
General Info				

## About Chemotherapy & Hormonal Treatments

- ◆ Whether you are a candidate for other therapies depends on the size of your tumour and whether the lymph nodes are involved. These therapies include chemotherapy and/or hormonal therapy.
- ◆ Chemotherapy is a treatment program of drugs designed to kill cancer cells. Chemotherapy is usually given intravenously (through a needle inserted into your hand or arm) or as a combination of intravenous infusion and pills taken by mouth. The treatments last from 3 to 6 months. Women often lose their hair from the chemotherapy but it always grows back after the treatment is over. During the treatment, many women also complain of a loss of energy. Some women may have an upset stomach and/or experience vomiting. This can often be prevented or controlled with mild medication.
- ◆ Hormonal therapy is offered to women if the tests done on the tumour show that there are receptors for female hormones on the cancer cells. Hormonal therapy is given in pill form. One pill is taken daily for 5 years. This pill is generally very well tolerated. Side effects may include hot flashes, nausea and weight gain. One of the more common types of hormonal therapy is Tamoxifen.



Surgeon's Name \_\_\_\_\_

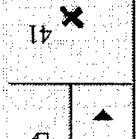

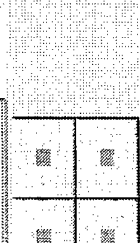
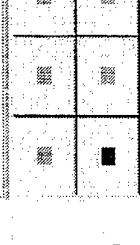

Telephone Number \_\_\_\_\_

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Appendix B: Computerized Node Positive Decision Board – CMF  
Description of Choice

Description of Choice	Side Effects of Choice	Outcomes of Choice
		
		
		

No Chemo





























CMF

AC

CEF


General Info

**CMF Treatment Cycle:**

	Day 1	Day 2	Day 3	Day 4	Day 5	Day 6	Day 7
Week 1							
Week 2							
Week 3							
Week 4							

- Each treatment cycle lasts 4 weeks.
- 3 chemotherapy drugs are given during each treatment cycle:
  - Cyclophosphamide is taken by mouth (pills) at home every day for the first 2 weeks of every treatment cycle, and
  - Methotrexate and Fluorouracil are given intravenously (through a needle) during clinic visits at the start of each treatment cycle and again one week later.
  - It takes about 20 minutes to receive the intravenous drugs.
  - The treatment cycle is repeated 6 times for a total of 6 months.

Appendix C: Computerized Node-Positive Chemotherapy Board –  
Overview Panel

	<b>Description of Choice</b>	<b>Side Effects of Choice</b>	<b>Outcomes of Choice</b>
 <b>No Chemo</b>	Description	Side Effects	Outcomes
<b>CMF</b>	Description	Side Effects	Outcomes
<b>AC</b>	Description	Side Effects	Outcomes
<b>CEF</b>	Description	Side Effects	Outcomes
<b>General Info</b>	Introduction	The Decision Board	

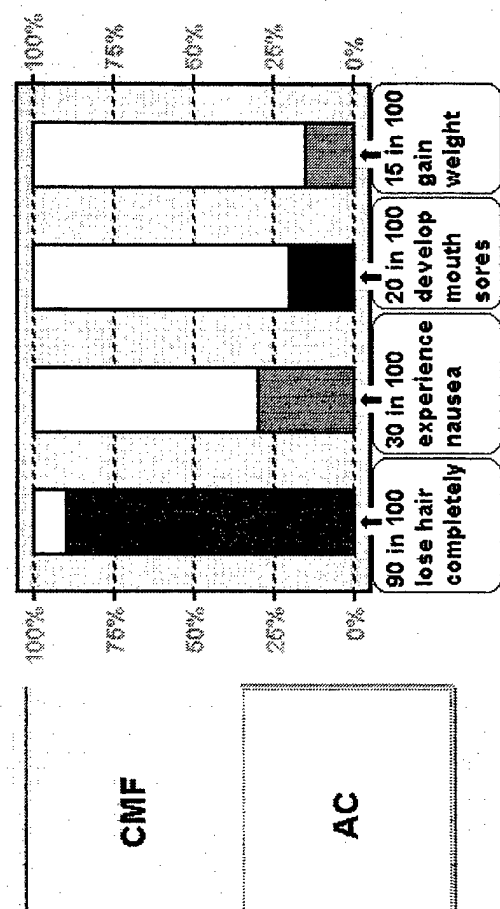
Appendix D: Computerized Node-Positive Decision Board – AC Side  
Effects Panel

Description of Choice		Side Effects of Choice		Outcomes of Choice	
■	■	■	■	▲	□
■	■	■	■	▼	▶
■	■	■	■	▲	□
■	■	■	■	▼	▶

No Chemo

45 X

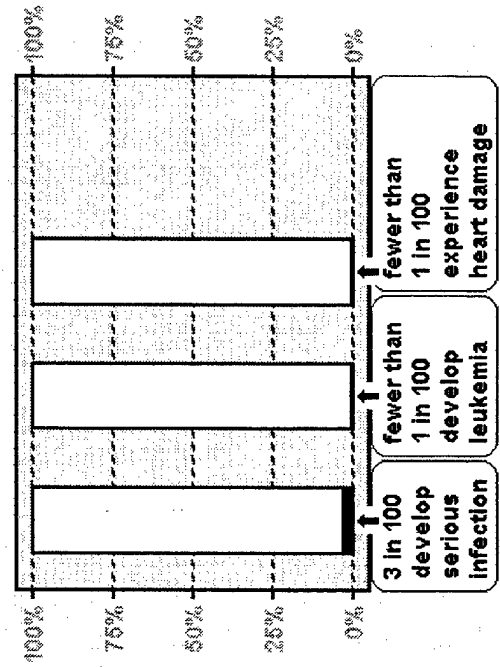
**Chances of common side effects:**



CMF

AC

**Chances of rare but serious side effects:**



CEF

General Info

- Complete hair loss occurs in most women taking AC.
- Other common side effects such as nausea and mouth sores occur less frequently among women taking AC than among those taking CMF or CEF.

- The chance of experiencing serious side effects such as leukemia (1 in 500 women) and heart damage (1 in 500 women) is slightly higher than with CMF but lower than with CEF.