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TITLE: Effects of Alternative Decision Support Technologies on
Breast Cancer Patients' Knowledge of Options and
Satisfaction with Treatment Decisions

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13. ABSTRACT (Maximum 200 Words) The objectives of the research are to (1) develop an innovative computer-based decision support system (CDSS) that will enable women with breast cancer to integrate the information available to them, understand diagnoses, treatment options and risks associated with treatment options, construct and structure their preferences, and make important health decisions; and (2) assess the impact of the new CDSS by making it available to women newly diagnosed with breast cancer and comparing it with two other existing technologies and a control group in a carefully designed experiment. The assessment of the impact will be made in terms of understanding of diagnoses, treatment options and risks associated with treatment options, satisfaction with decisions made, amount of involvement in decision, compliance with decision, change in health status, and change in quality of life. This report details the progress made in further enhancements to the CHESS system. The study design and protocol are described as well as the survey instruments developed for this study. The recruitment process is summarized and preliminary results given.				
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FOREWORD

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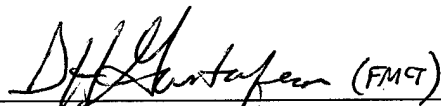
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(5) Introduction:

The objectives of the proposed research are to (1) develop an innovative CDSS that will enable women to integrate the information available to them, understand diagnoses, treatment options, and risks associated with treatment options, construct and structure their preferences, and make important health decisions; and (2) assess the impact of the new CDSS by making it available to women newly diagnosed with breast cancer and comparing it with two other existing technologies and a control group in a carefully designed experiment. The assessment of the impact will be made in terms of understanding of diagnoses, treatment options, and risks associated with treatment options, satisfaction with decisions made, amount of involvement in decision, compliance with decision, change in health status and change in quality of life.

Specifically, we will compare three types of decision support technologies to a control group:

1. CHES: a new CDSS designed specifically to meet breast cancer patients' needs;
2. Internet: the rapidly proliferating Internet technology;
3. Audio Tapes: an audio-tape series produced by the National Coalition for Cancer Survivorship called Cancer Survivor Toolbox. This self-learning audio program is designed to assist patients diagnosed with breast cancer from the time of diagnosis through the rest of their life.
4. Control: standard patient education and any of the following books: Dr. Susan Love's Breast Book, Celebrate Life (a book on breast cancer aimed specifically at an African American population), and Breast Cancer? Let Me Check My Schedule.

(6) Body:

- Statement of Work Task 1

Development and test of CHES enhancements (Months 1-15)

Develop and test new decision aid and demonstration program.

Accomplished in Year 1 (see previous report)

- Statement of Work Task 2

Acquire and Prepare Equipment (Months 9-12)

Accomplished in Year 1 (see previous report)

- Statement of Work Task 3

Refine research materials (Months 8-10)

Modify CHESS user manual to reflect the CHESS enhancements.

Develop user manuals for the Internet technology.

Develop and pilot test data collection forms.

Accomplished in Year 1 (see previous report)

- Statement of Work Task 4

Train staff from sites (Months 13-15)

Train site coordinators in study goals and rationale, subject identification and accrual, data collection, Internet installation and operation, and support for the video. Sites are previously trained in CHESS installation and operation but will be updated for CHESS enhancements.

Deliver materials to sites describing the project and conduct field tests of recruitment and study operation

The sites involved in this grant include University of Wisconsin Comprehensive Cancer Center (Madison, Wisconsin), Mayo Cancer Center (Rochester, Minnesota), University of Wisconsin – Milwaukee School of Nursing (Milwaukee, Wisconsin). Dr. Gustafson and/or Dr. Sainfort completed initial site visitations in July 1999. Ms. McTavish (the Project Director) followed up the visits by Dr. Gustafson and Dr. Sainfort with training sessions with each site coordinator. This included step by step review of the protocol (see appendix #1) from recruiting study participants, the randomization process, installing computers (or other interventions), in home training of study participants in use of the Internet and CHESS, setting up Internet Service Providers, documentation necessary for each study participant, removing computers, use data collection, as well as general study protocol.

- Statement of Work Task 5

Recruit subjects, pre-test, assign and install (Months 16-30)

15 months after funding we will begin recruiting subjects, pre-testing, randomizing for the 4 groups, and installing software and Web TVs (note: As described in Year 1 annual report – laptop computers were used instead of Web TVs.

The major emphasis of our work this year has been around recruiting subjects. To date there are 174 study participants on study. We had projected that we would have 240 subjects in study by this time. The major reason for our deficit in recruitment was due to the delays in receiving final IRB approval from Mayo Cancer Center. Recruitment has steadily increased since Mayo began recruiting. The second area of difficulty we have had in recruitment is recruiting Women of Color. Our current site, UW – Milwaukee School of Nursing found it much more difficult to reach African American women than the expected. As a result we are in the process of adding a recruitment site at Wayne State University in Detroit, Michigan. Recruitment at this site will be exclusively of African American women. We expect final IRB approval from Wayne State

University by August 1, 2000. This will help us reach our goal of 400 participants completing the study (see Appendix #2, Monthly Recruitment Rate Graph).

- Statement of Work Task
Operate CHESS (Months 16-34)

Our first study participants were using CHESS beginning in July 1999. All study participants who are randomized to the CHESS group, or the Internet receive a laptop computer, basic Internet training as well as how to search the Net. For those in the CHESS arm of the study they also are trained on navigating within the CHESS site. A toll free number for technical assistance as well as a toll free line for inquiries for all arms of the study have been supported since July 1999. As described in the grant, a trained facilitator oversees the CHESS discussion group to make sure that erroneous information is not transmitted. In addition all questions submitted to the Ask an Expert service of CHESS have been answered within two business days. Along with the daily operational tasks to keep CHESS running smoothly continual development and updating of the material in CHESS was and continues to be a focus of our work. Information has been updated or added to the following CHESS services: Questions and Answers, Instant Library, WebLinks, About CHESS, and Decisions, Decisions. Within Decisions, Decisions we have added a direct link to the Department of Defense Cancer Decision Guide. There were also three new services added to the Breast Cancer module this year: Journaling, Video Gallery, and Live Chat Events.

- Statement of Work Task 7
Collect Post-test data (Months 16-39)

Short form (1 page) decision surveys will be sent at weeks 2,4,6,8,and 10. Longer form surveys will be sent to study participants at months 3 and 9. All surveys will be returned to the Madison Project Office.

Returns will be closely monitored to be sure the surveys are promptly returned and complete.

Follow-up contacts (including interviews, if needed) will collect surveys not returned and fill in incomplete or illegible data.

Copies of all the surveys for this study are attached as appendices (Appendix # 3: PreTest, Appendix # 4: 2,4, & 6 Week Survey: Appendix # 5: 2 Month Survey: Appendix # 6: 4 Month Survey: Appendix # 7: 9 Month Survey). The schedule of surveys has changed slightly from the original proposal, however the data being collected has not changed. The 10 week survey was eliminated since the majority of patients had finished making their treatment decisions at the 2-month (or 8 week mark). Additional items were added to the 2-month survey beyond decision satisfaction including quality of life measures, health care utilization, mood scales, doctor patient relationship satisfaction and coping scales.

Three days after a survey is sent out the study participant is called to make sure she received the survey and encourage her to fill it out as soon as possible. To date our survey return rate is over

94%. If the survey does not come back in one week from the date it is sent out, a follow up call is made to remind the participant that we are waiting for their survey. If the survey does not arrive within 2 weeks of the date it is sent we call one last time and attempt to fill out the survey over the phone with the participant. If the study participant is unwilling to do this, or we are not able to reach the study participant we send a duplicate letter to them with a letter explaining that their survey data is critical to the research. If they do not return that survey no further follow up attempts are made. As mentioned above our success rate of completed surveys is extremely high and we will continue to follow the protocol outlined above through out the study.

- Statement of Work Task 8

Remove computers (Months 20-34)

Computers will be collected from users after four months in the home.

Each study participant who is randomized into the CHESS or the Internet arm of the study is given a computer with Internet access for five months. The original proposal recommended access for four months. However after having focus groups and reviewing our past research access was increased by one month in order to allow women access to the Internet and/or CHESS throughout the majority of their treatment for breast cancer. The computers are collected at the five-month mark and Internet access is canceled at that time. The computers are cleaned, tested and put back in the filed for use by other study participants.

- Statement of Work Task 9

Prepare the data for analysis (Months 17-40)

Survey data is prepared for analysis upon receipt of the survey. The project director (Ms. McTavish) reviews each survey within two days of receiving the survey to make sure all questions are answered and to determine if any answers need clarification. If there are questions or clarification is necessary a project assistant calls the study participant and clarifies the answer in question. If a portion of the survey has been skipped, that section of the survey will be duplicated and sent back to the study participant with a note asking them to fill out the marked portions.

The majority of surveys completed by study participants do not need further clarification and are added directly to our SPSS survey database by a student. Once the student has entered the data it is double-checked by a Research Assistant. As mentioned earlier there is a 94% return completion rate of the surveys.

- Statement of Work Task 10

- Conduct Secondary Analyses (Months 20-36)

- Begin baseline and secondary analyses.

- Describe the study population and examine similarities and differences of the 4 groups.

- Exploratory analyses will begin with this initial data set.

Preliminary analysis of the survey data as well as the use data has been ongoing. The age range for the entire study population is 26 years old to 80 years old with the mean age being 52.07 years old. The mean age range for the four interventions differ by 5 years (rounded to the nearest year). The mean age of the four interventions are as follows: CHESS; 50 years old, Books; 51 years old, Internet Only; 54 years old and Audio-tapes; 55 years old. As the number of participants in the study increases we expect the age difference to lessen.

Preliminary analysis of subject's responses to a series of questions about treatment decisions highlights the importance of early intervention in providing assistance with decision making. The number of decision under consideration drops off quickly during the weeks following diagnosis and surgery. By the two month mark, over one third of the subjects indicated they had no treatment decisions to consider. While decisions regarding chemotherapy were cited most frequently as the most important treatment decision, subjects cited a wide range of other topics requiring decisions including different surgical and non-surgical options. While those who received an intervention prior to surgery were focused on issues such as whether to have a lumpectomy or mastectomy, lymph node sampling, and breast reconstruction; the issue of chemotherapy, tamoxifen and clinical trial participation were the most important decisions after surgery.

Regarding the decision making process, one preliminary finding of interest is an apparent tendency of the subjects in this study to change regarding their desired role in decision making over time. Based on these early results, it appears that, as their treatment progresses, women move away from wanting to make the final decisions regarding their treatment to wanting to share this decision making with their provider. It is too early to tell whether there are any difference in this preference for participation between subjects in different intervention groups.

At this time we have had a very small number of subjects who have completed the entire study. We have completed some preliminary analysis of the computer use and outcome data for the first 40 people (23 randomized to CHESS and 17 randomized to the Internet) who completed the study. Results indicate that the CHESS and Internet groups use the computers very differently. Overall, the CHESS group use the computer approximately 4 times as much as the Internet group. For every minute of use of the computer by the Internet group, the CHESS group uses the computer for four minutes. Of that time, over 45% of the use of the computer of those in the CHESS group are health related (even though there are links to non-health related sites) where as only 20% of the use of those who are in the Internet group are health related. We are also finding substantial difference in most outcomes (functional health status, negative emotions, and participation in health care, self-efficacy, and breast cancer related concerns). Those who have access to CHESS having better outcomes than those who get the Internet do. It is too early to

examine statistical significance at this time however the trends suggest that there may be important differences.

- Statement of Work Task 11
Conduct Primary Analyses (Months 40-45)

The work for this task will take place after this annual report.

- Statement of Work Task 12
Prepare Final Report and Other Publications (Months 22-45)

The majority of the work for this task will take place after this annual report.

(7) Key Research Accomplishments

- Trained site coordinators at University of Wisconsin Comprehensive Cancer Center, Mayo Cancer Center and University of Wisconsin School of Nursing
- Updated CHES
- Recruited 174 study participants
- Operated CHES
- Collected and cleaned survey data
- Began preliminary computer use-data analysis and survey data analysis:
 - Those in CHES arm of study use the computer 4 times as much as the Internet use.
 - Substantial difference in functional health status, negative emotions, and participation in health care, self-efficacy, and breast cancer related concerns.
 - Over 45% of CHES group's computer use is health related, only 20 % of the Internet group's use is health related.
 - Most treatment decisions are completed by the 10-week mark.
 - Desired role of patient in decision making process appears to change over time.
- Began preliminary survey data analysis

(8) Reportable Outcomes:

Not applicable at this time

(9) Conclusions:

It appears that as a woman progresses through breast cancer treatments, women move away from wanting to make the final decisions regarding their treatment to wanting to share this decision making with their provider.

Also initial results indicate that the two groups who received computer intervention (CHESS and Internet only) used the computers very differently. Those receiving CHESS used the computer 4 times as much as those who only received the Internet. 45% of the computer use of the CHESS group was accessing health information where as only 20% of the use of those who are in the Internet group is health related. Substantial difference in most outcomes (functional health status, negative emotions, and participation in health care, self-efficacy, and breast cancer related concerns) have also been seen. Those who have access to CHESS having better outcomes than those who get the Internet do. It is too early to examine statistical significance at this time however the trends suggest that there may be important differences.

(10) References:

Not applicable at this time

Addendix # 1

MAYO CLINIC DOD Study Protocol

RECRUITMENT;

Introduction by the Physician and the Nurse

Both the physician and the nurse play an important role in the recruitment of patients. Their support and enthusiasm is crucial. They are the first people to introduce the patient to the idea of being involved in the study. Their support reassures the patient that the study is valid and worthwhile. The site coordinator can then build on the positive base which the doctor and nurse have begun to establish. Even though the doctor and nurse do very little explanation of the study, their endorsement is crucial in getting patients involved.

Patient Introduction to Research Study by the Physician:

All women 18 years or older diagnosed with breast cancer within two months at the University of Wisconsin Comprehensive Cancer Center, UW Milwaukee School of Nursing and Mayo Clinic in Rochester MN will be asked to join the research study except for those who: 1) are homeless; or 2) cannot read and understand sample questions from the pre-test survey.

They will be asked at their first appointment at the clinic. The attending physician will be the first person to introduce the research study to the patient. The physician will briefly discuss the importance of research in general and more specifically why he/she endorses this study. The physician will mention that the site coordinator will explain the study to the patient and answer any of their questions.

Suggested Introduction of Study by Attending Physician to Patient:

"We presently have a research study taking place which you may be interested in joining. The study is about information and support patients receive. The only way that we can find out what sort of information and support is most helpful to patients diagnosed with breast cancer is through studies like this. I'll have the nurse introduce you to the site coordinator of the research study before the end of your visit today. I hope you'll consider participating in this study. "

Nurse's Interaction with Patient Regarding Study:

The nurse will encourage the patient to participate in the research study that the attending physician briefly discussed with her. The nurse should screen out any patients known to be homeless or illiterate, under 18 years of age, or more than 2 months past the initial treatment for breast cancer, letting the patient know that the study is not appropriate for them. The nurse will discuss that the cancer clinic (or hospital) is excited to be a part of this study because it is first and foremost beneficial to the patient. At this point she will introduce the site coordinator to the patient. The site coordinator will describe the study in more detail and answer any questions the patient may have.

Suggested Introduction of Study Coordinator by the Nurse:

"I'd like to introduce _____ (site coordinator's name). She is the site coordinator for the research project which Dr. _____ briefly described to you. The purpose of the study is to see what sort of support and information is most helpful to patients. We are fortunate to be one of three sites that are taking part in this study. The project is funded by the Department of Defense. I'll let _____ (site coordinator's name) tell you more about the research study and how you can get involved. She'll be able to answer any of your questions. I'll be back in a few minutes to see about scheduling your next appointment with Dr. _____."

The Site Coordinator / Study Introduction:

The site coordinator plays an important role in making the patient feel comfortable in the midst of hearing very difficult news. Site coordinators are chosen for their sensitivity to people in crises, their belief in research, and their excitement for the CHES project. (To date, we have had very effective results in breast cancer patients accepting CHES upon diagnosis, with approximately an 80% acceptance rate).

The site coordinator begins by reintroducing themselves to the patient and acknowledging the fact that this is a very difficult time for the patient. They go on to explain why the research project is important, what the research project entails, including the benefits to the patient as well as benefits to future patients and research in general. It is important to build a sense of trust with the patient quickly.

Suggested Explanation of Project to the Patient by the Study Coordinator:

"As _____ (the nurse's name) mentioned, I'm _____ (your name), the site coordinator for a research project funded by the Department of Defense. I realize this is a difficult time for you and in some ways I feel awkward bringing up a research project in the midst of this. However I'm committed to this project because I believe it will benefit you as well as other patients in the end."

"All patients who are within two months of diagnosis for breast cancer are eligible for the study, except for those who are less than 18 years of age, those who are homeless and those who cannot read. Do you fall into any of these categories? I don't need to know which one."

If patient answers yes, say "Thank you, but I'm afraid this study won't be appropriate for you. Thank you for your time. I'll let the nurse know that you are waiting for her."

If patient answers no, explain the study to the patient.

Explanation of the DOD study:

"We are trying to see what kind of information and support is most helpful to patients diagnosed with breast cancer. The study has four groups. All of the groups will receive information about breast cancer, but they will get the information in different ways. The first group will get a set of audio tapes called The Cancer Survivor's Toolbox. Tape recorders will be available for those patients who need them. The second group will receive any or all of the following books: Dr. Susan Love's Breast Book, written specifically for women with breast cancer; Breast Cancer? Let Me Check My Schedule, a book written about the experiences of ten professional women who all experienced breast cancer; and Celebrate Life, a book that highlights about 40 stories of African American women dealing with breast cancer.

The third and fourth groups will get information about breast cancer by having a computer placed in their home for five months. One of the groups will get a computer program called CHES. CHES stands for the Comprehensive Health Enhancement Support System. CHES has a variety of services in it, including up to date information about breast cancer and the ability to be connected to other women who have breast cancer. Also, since CHES uses the Internet, they will also receive free Internet access as well. The other group will get a computer that only has Internet access. Both services will be provided at no cost to the participants.

No computer experience is necessary to be a part of this study. We will provide training on both systems. The computer will be in your home for 5 months. There is no cost to you! Again, don't worry if you know nothing about computers, **absolutely no computer experience is needed.**

I cannot guarantee which group you will be in as people are randomly placed in one group or the other. If you are in a group that gets a computer, there will be a training session provided. Each participant who gets the computer is given a code name to ensure their anonymity. As I mentioned to you earlier, this would not cost you anything. Since the computers are laptops, the only thing you will need to have at home is an electrical outlet to provide power to the computer and a phone jack in order to connect to the Internet.

Each person agreeing to be in the study regardless of which group they are in will need to fill out a total of seven surveys. You will be reimbursed for every survey you fill out. The first one will be filled out now, and the rest of the surveys will be mailed to you. There are three short surveys which will take about ten minutes each. You will get \$5 per survey for filling those out. The others are longer and will take about 20-30 minutes to fill out. You will get \$15 for each of the longer surveys. You will be reimbursed a total of \$75 over the course of the study. It is very important that you complete the surveys and send them back in the self addressed envelope as soon as possible. Other than filling out these surveys however you have no further responsibilities to this study. Also, your survey answers remain anonymous. If you decide to participate in the study, you are assigned a number, which is the only identification on any data we collect. I will be the only person who has both your name and number other than the project director. This information will not be accessible to anyone else. It will be kept in a locked file drawer. Also, I will not see any of your answers from the surveys. I will simply take down the pre-assigned identification number on the returned envelope, and pass that envelope (still sealed) to the data survey processors.

This research study will not affect the treatment you receive in any way. Your doctor will not know whether or not you agreed to be in the study. There is absolutely no cost to be involved in this study, in fact, as mentioned earlier you would gain a total of \$75.00 just by filling out the surveys.

Just as you benefit from taking part in this study we benefit also. We get your feedback on what information is most helpful to patients. This helps us to develop material that meets the needs of patients. Without your input we can't do this nearly as effectively.

Would you be willing to be part of this research study?"

If the patient says yes, they would like to be in the study, be sure to ask them whether they are pre-treatment or post-treatment. This will be important for randomization.

RECRUITMENT, Patients Responses, What Next?

- **NEGATIVE RESPONSE:**

Ask them if they would be willing to answer some questions of why they decided not to be in the study. Verbally go over the "Declined To Be In Study" sheet with them.

Be sure to thank them for their time.

- **POSITIVE RESPONSE:**

Thank them for their willingness to participate in this study. Ask them to please fill out the consent form to be a study participant. If they cannot answer the survey questions, let them know that they are not eligible for the study since we cannot get the data we need from them. After they have filled this short form out, fill out the basic information on the tracking form, name, phone number(s), address... You will then give them the Pre-Test survey to fill out. Make sure that the control number on the top of the survey is the same number as on the tracking sheet. Ask the study participant to fill out the survey and when she is finished to put it in the brown manila envelope and seal it.

Let her know that you will be outside while she fills out the survey. Also let her know that when the nurse returns to schedule her follow up appointment you will pick up the survey. At that time you will let them know which group they are in.

RANDOM ASSIGNMENT:

Once the pre-test is returned, the subject will be randomly assigned to one of the groups. Each site will have two sets of envelopes, which contain a randomly generated assignment to the study groups. One set of envelopes is for women who are pre-treatment, the other for women who are post-treatment. The envelopes are in numerical order and must be opened in order. The number on the envelope will be the person's code number. Open an envelope from the appropriate set to determine which of the following groups the research participant will be assigned. Mark this information on the tracking sheet, which you have for the participant. If she is in a group that gets a computer, when you inform her of which group she is in, schedule a training time with her. If she is in the group that gets the audio cassettes, make sure she has a tape recorder. If she does not have one available, offer one to her as part of the study. If she is in the control group, give her any or all of the following books: Dr. Susan Love's Breast Book; Breast Cancer? Let Me Check My Schedule; and Celebrate Life. No matter which group she is in let her know you will call her in a week to see how she is doing.

A: Control Group:

If she is assigned to the Control Group the site coordinator will give the study participant a copy of any or all of the following books: Dr. Susan Love's Breast Book; Breast Cancer? Let Me Check My Schedule; and Celebrate Life, along with your phone number in case she has any questions. The site coordinator will also call the study participant one week from their agreeing to participate in the study to see how she is doing and answer any questions she may have about the study.

The site coordinator should also let the study participant know that she will receive \$15 for completing the pre-test survey within two weeks. If the participant fills out the pre-test survey at a later date, tell her the survey needs to be returned within a week. Mention that the next survey will come in the mail in two weeks, and that the next few surveys will come at two-week intervals so there will be quick turn around time between filling out the surveys and getting the next one. The name of the study participant should not appear on the survey or on the return envelope.

The recruiter must send the information from the tracking sheet to Fiona (the project director in Madison) by email or fax (Fmctavish@chsra.wisc.edu; FAX: 608.263.4523; Voice: 608.262.7852). This will let Fiona know that participant # _____ needs to be reimbursed for the pre-test. If the participant does not receive a reimbursement within four weeks, she should contact the site coordinator who will look into the matter.

B. Audio Cassette Group:

If the study participant is assigned to the Audio Cassette group, the site coordinator should make sure she has a tape recorder available. If she does not, the site coordinator should offer her one as part of the study, which she can keep.

Like the other study participants, the experimental group will receive a phone call from the site coordinator one week after joining the study to make sure they are doing okay.

The site coordinator should also let the study participant know that she will receive \$15 for completing the pre-test survey within two weeks. Mention that the next survey will come in the mail in two weeks.

The recruiter must send the information from the tracking sheet to Fiona (the project director in Madison) by email or fax (Fmctavish@chsra.wisc.edu; FAX: 608.263.4523; Voice: 608.262.7852). This will let Fiona know that participant # _____ needs to be reimbursed for the pre-test. If the participant does not receive a reimbursement within four weeks, she should contact the site coordinator who will look into the matter.

C. Computer Groups:

If the study participant is assigned to one of the groups that get a computer the site coordinator will set up a time to train them in the clinic that day, if possible. They should spend 45 minutes to an hour training them. The site coordinator will need to set up the Internet connection before the computer can be used in the home.

The research project will pay for the Internet connection for the five months that the computer is in the home. When the computer is removed from her home (5 months after installation), the Internet connection will be disconnected.

Like the other study participants, the computer group will receive a phone call from the site coordinator one week after joining the study to make sure they are doing okay. This also allows the site coordinator to answer any questions the participant may have regarding the study in general or questions they may have regarding the computer.

The site coordinator should also let the study participant know that she will receive \$15 for completing the pre-test survey within two weeks. Mention that the next survey will come in the mail in two weeks.

The recruiter must send the information from the tracking sheet to Fiona (the project director in Madison) by email or fax (Fmctavish@chsra.wisc.edu; FAX: 608.263.4523; Voice: 608.262.7852). This will let Fiona know that participant # _____ needs to be reimbursed for the pre-test. If the participant does not receive a reimbursement within four weeks, she should contact the site coordinator who will look into the matter.

Site Coordinator Protocol for Interaction with Study Participants:

The site coordinator will call all research participants (regardless of which group they are in, experimental or control) one week after initially joining the research study to see how she is doing and ask if she has any questions regarding the study.

General Phone Call Etiquette:

- Introduce yourself and remind the study participant that you are the research site coordinator that they met at the hospital.
- Ask if this is a good time to talk or should you call them back at a later time?
- Ask how they are doing, feeling ...
- Ask them if they have any questions regarding the study.
- If the phone call is regarding post-test surveys, ask the participant if they received the survey, and remind them to fill it out and return it as soon as possible.
- Thank them for their time and let them know they can call you if they have any questions.

UW Madison Phone Calls

The UW Madison will call all research participants three days after sending out the two, four and six week surveys. The purpose of this phone call is to be sure that they received the survey and to remind them to complete it and send it back in the pre-addressed envelope. The site coordinator should call the participants one-week after sending out the two-month, four-month and nine-month post-tests. If the post-test survey is not returned within a week, a second phone call will be made and a second survey will be mailed out if necessary. If the survey is still not returned within another week, the site coordinator will try to collect the data by phone interview.

Installation Protocol:

The site coordinator will install computers in the patient's home. The following is an outline of the installation process, followed by an outline of how to walk a person through CHESS and/or the Internet for the first time.

Computer Installation: Phone call to Arrange Installation Time:

- 1. Re-Introduction**
 - a. Name
 - b. Connected with Mayo Clinic, CHESS Research Project - funded by DOD
- 2. Hardware Requirements**
 - a. Electrical Outlet
 - b. Phone Jack
- 3. Information Installer Needs**
 - a. Rotary or Touch-tone Phone lines
 - b. Call Waiting? Y/N
 - c. Is it long distance to the city where the Internet provider is located? Y/N
 - d. Ask the user to choose a codename and password. Explain to them that each time they use CHESS they will need these codes to "log in." These also assure the user of anonymity. Suggest that they write these codes down on a piece of paper and put them in a safe place so they have them in case they forget them.
 - e. Time and Date to install computer
 - f. Explain that installation usually takes about an hour
 - e. Get directions to house if the installation will be in the home
 - f. Complete address (zip code and phone number and correct spelling of name.)
- 4. Restate date and time of Computer Installation or training in the clinic**

CHES: Pre-Installation Checklist for Installer

1. CHECKLIST

- ☐ Set up an Internet connection.
- ☐ Enter the codename and password of the person before the installation date. To do this, go to <http://chess.chsra.wisc.edu/admin/>. This will take you to the Remote Administrative Tools section.
 1. Login using **codename:** dod and **password:** Thistle.
 2. Select the Living with Breast Cancer Module.
 3. Select a chapter (in this case, DOD).
 4. Choose Add a New User.
 5. Put in the pertinent information on the *Add a New CHES User screen.
*make sure to always mark NO for the CHES Expert because that is only marked YES if the person being registered is the one who answers the Ask and Expert question as the Expert.
 6. Choose the discussion groups the woman will be allowed to use.

CHES: Computer Installation

1. Equipment to Take:

- 2 laptops with carrying cases
- 1 power cord for the laptop
- 1 Telephone line cord
- Telephone cord extension adapter
- Telephone line adapter (splitter)
- 2 to 3 prong electrical plug adapter
- mouse

2. Misc. Items to Take:

- CHES Breast Cancer User Support Materials
- For the patients who receive Internet only, bring the information about the Web to leave with them.
- Telephone number, address and directions to participant's home
- Help Line phone number (1-800-480-9223) in case there are any problem
- Map of the area

3. Setting Up the Computer

- a. Ask where computer can be placed
- b. Find telephone jack
- c. Find electrical outlet
- d. Set up computer (This should take about 5 minutes)

**Always take an extra Laptop with you
just in case there is any trouble with the original one.**

**Be sure you are comfortable with setting up
computers before taking one out to install!**

1. WALKING THE PERSON THROUGH CHESS AND/OR THE INTERNET

(This should take 40 to 50 minutes. If other family members are there and want to be involved it will take approximately 10 more minutes).

- a. **Reassure** the person that no computer experience is necessary and that everything you will be telling them is in the User Support Materials and on the computer screen. They can also call you or the Help Line (1-800-480-9223) if they have any questions.
- b. **Turning on the computer**
Use the power switch on the laptop to turn the computer on.
- c. **Describe the keyboard and mouse** to the user. Explain to them that while there is a finger mouse provided on the laptop, we will also give them a separate mouse, which may be easier for them to use. ****Remember that the external mouse needs to be plugged prior to turning on the computer.** Have the user sit down at the computer and use the keyboard and mouse as you walk them through CHESS. If they have never used a mouse before, let them use it to get a feel for how it works before you begin.
- d. **Show her how to log on to CHESS** using her code name and password.

2. TRAINING FOR THOSE WHO RECEIVE CHESS WITH INTERNET ACCESS:

To begin training, click on the browser icon on the desktop. The CHESS Start page will come up. Using the CHESS site, begin the training by going over some basic Internet skills. **Sign on with her codename and password to begin training.**

- a. **Explain** the navigation functions of the browser:
 - **Back/Forward Button**
The BACK and FORWARD buttons are located on the browser toolbar at the left hand side of the screen. The BACK button allows the user to jump back to the previous screen you were viewing. The FORWARD button allows them to move forward in the same way.
 - **Scroll Bar**
Show the user how to move the screen up or down by either clicking on the bar with the left hand mouse button and dragging the mouse up or down or by using the arrows at the top or bottom of the screen.
 - **Home**
Explain to the user that this will always bring them back to the CHESS Home Page.
- b. **Highlight** the fact that when the cursor moves over a link, it changes from an arrow to a hand. This will help the user find links when they are in the form of pictures or other graphics.
- c. **Show** the user the way that a hyperlink changes color when they have already visited it.
- d. **Show** the user how to use the mouse and click into a search box in order to begin typing the words for the search.
- e. **Demonstrate** how to use the search engine Alta Vista (www.altavista.com). Use the help section provided on the page to show the user different ways to search and then try searching for something they are interested in. A suggestion would be to have them search for "dogs", and then, to narrow the search, search for "police dogs." This will give them an idea of how many entries will can come up for a general topic, as well as how to narrow their search topic.

Next, move on to the CHESS specific navigation of the **Tool Bar**. After the explanation of each section, click on the word to give the user an idea of what happens in each section of the Tool Bar:

- a. **Topics** This section allows you to search CHESS by specific topics such as treatments, menopause, emotional support or pain. You can click on a word and select a topic you are interested in finding out about.
- b. **Dictionary** CHESS has a dictionary of words that are medical and/or technical in nature that relate to breast cancer. By clicking on the Dictionary button on the toolbar, you can find the meaning of words you may not be familiar with.
- c. **Bookmarks** This section of CHESS allows you to "mark your place" and come back to information you may be particularly interested in.

- d. Keywords** To search for a specific topic by keyword such as, menopause, emotional support, or pain, click the Keyword button on the toolbar. The keywords are organized using the alphabet. You can click on a letter to see the list of keywords that begin with that letter. To search for a specific keyword, type the word into the search box provided. You can get a complete list of the keywords by pressing the search button without typing anything in the box.
- e. Help** You can click on the Help button no matter where you are in CHESS and information for that particular part of the website will come up.
- f. Services Menu** Show that the CHESS Services are divided into 8 areas (Overview of Breast Cancer, Decisions and Planning Guides, Personal Space, What's New, Reading Room, Other Sites, Connecting with Others, and Beginners Guide). Click on Beginner's Guide. Show how to get descriptions of each service by moving the mouse over the service.

3. EXPLAINING THE CHESS SERVICES:

Using the Services link at the lefthand side of the screen, take the user back to the Services page. From here, explain the services provided on the website. The following list is **IMPERATIVE** to go over in detail with the participant. The other services can be touched on verbally in the course of the training session.

a. Overview of Breast Cancer

This section is provided to help women who have been recently diagnosed with breast cancer and who are just beginning the search for information about the disease. It contains basic information about breast cancer and the treatment options available.

Click into Overview of Breast Cancer and click on the first link in the list, Breast Cancer Basics. Read the short paragraph provided. Click on the middle photo to watch the video clip of Linda. Take the opportunity to show the woman where the volume control is on the computer. You will need to turn it up. Once you have viewed the video, use the back button. Show the user the options to look at Questions and Answers, Instant Library and Personal Stories that relate to the basics of breast cancer. Go quickly and show them the list of questions that are available in Questions and Answers, the list of articles in Instant Library and the list of Personal Stories. Explain that this is a condensed list, but that they could click on any of the Q/A to go directly to that question... Return to the Services menu by using the Navigation Bar.

b. Questions and Answers

Questions and Answers provides answers to the most commonly asked questions by women with breast cancer, their partners, and family. There are about 500 questions in the breast cancer module.

The user can look up questions through topics, such as diagnosis, treatments, prevention, emotions..., or they can use the Search function and type in a word they are interested in knowing more about. The search will bring up a list of questions that include that particular word. Ask the woman to whom you are demonstrating CHESS to click on the link to Questions and Answers.

Have the woman click on the word "Treatments." This brings up another list of options, from which she should choose "Surgery", and then "Questions to Ask Before Surgery". Have her choose the question "What questions should I ask Before Surgery?" and let her read the answer.

At the bottom of the page, there is a list of keywords. Explain that she can click on a keyword to get more information relating to the topic of the question. Have her choose the keyword, Doctors, Communication With. A box will appear telling the user which CHESS services have information on this topic. Click on the button for Instant Library. You will see a list of articles about talking to your doctor. Click on Talking with Your Doctor (middle of the list). The computer will that article. Explain that once the user has finished reading the article she can go to other CHESS Services that have information on that same topic or return to Questions and Answers. Return to the Services page by using the back button or clicking on the Services Menu link on the top left of the screen on the Navigation Bar.

c. Web Links

Next take the user to the Web Links section from the Services page. Explain to the user that Web Links is a list of web sites that the developers of CHESS have reviewed for content and reliability.

Click on Web Links and a list of web sites will come up. Have the user click on American Cancer Society. This will take you to a page with some information about the website. Go over this information with the user, explaining that the information is provided to give them basic information about each site we provide as Web Links.

Click on the URL link (which is the address of the site) to take you to the American Cancer Society site. Explain to the user that they have now exited the CHESS site and are now at the American Cancer Society website. Show them how they can return to CHESS by using the BACK button on the browser. Return to the Services page by having the user click on Services at the top left of the screen on the Navigation Bar.

d. Ask an Expert

This service allows the user to ask questions anonymously (the user is only identified by her code name) to an expert in the area of breast cancer. Questions can deal with issues such as medical, social, financial, spiritual, emotional... Explain to the user that the Expert works with a group of experts in various fields who can assist in answering questions that she may not be trained to answer. Questions are answered within 2 business days.

Have the user click on "Ask an Expert". Then have her click on "Ask the Expert A Question." A blank box will appear on the screen. Have her type "Who Are the Experts?".

Next, have her click on "Read Answers to Your Questions." The Welcome Message from the Expert should show up. Have her read the welcome message. Explain that if there are no new messages, it means the expert hasn't answered it yet. If she does not get a response from the Expert within 2 business days she should call the Study Coordinator so she can check to see that there are no computer problems.

During this time, you should also show the user the Open Expert messages. Explain that when the Expert gets a message from a woman that she feels is applicable to the entire group, she will take out all identifying information and will put it in the Open Expert section so everyone can read it. Show her how to use the keywords to look in the Open Expert section for topics she is interested in. To return to the Services page, click the button on the upper left of the screen.

e. Discussion Group

Explain that Discussion Group is a service that allows the user to talk confidentially and anonymously to other people who have access to the CHESS computer. There are several discussion groups which the user can take part in by reading and/or writing messages. The discussion groups are anonymous. No

one knows the user's real name, they only know each others' code names unless a user reveals their real name.

CHESS offers two types of Discussion Groups, World Groups and Local Groups. The World Groups can be used by anyone who has access to CHESS. Patients in specific local areas, as well as in different research studies will use Local Groups. Local groups are limited to approximately 40 users. The installer should set up which Local and World Groups that the user can be a part of before beginning the training.

If a family member wants to use the CHESS system, they need to get a codename and password from the site coordinator. They are more than welcome to use the system once they have these things.

Sending messages in Discussion Group works the same way as Ask an Expert. To read through messages, click on "Read New Messages." Any new messages will automatically appear on the screen (this might take a few moments the first time depending on how many messages there are). A list of all the messages will then appear on the screen. The newest messages will be on the bottom of the list. Click on the message you want to view. The message will appear. To reply to a message click on the "Write" button at the top or bottom of the screen. A blank box will appear on the screen (just like in the Ask an Expert Service). Show her how to write and send a message. Type out a message similar to the following: "Hi, this is Fiona and Cadillac trying out the computer and learning how the discussion group works. Talk to you more later, Fiona and Cadillac" Before actually sending the message, ask the woman if it is okay that you send the message (it will appear with her codename). If she says yes, go ahead and send it. This allows other women in the discussion group to know there is a new person on the system and they can then write her a message.

You should also explain the Discussion Group Archives and Introductions at this time. Tell the user that the Archives work like the Open Expert questions, except the Discussion Group facilitators do the work that the Expert does for Ask the Expert by taking the identifying information out of the answers if they want to post them in the Archives. The Archives are also linked by keywords.

Introductions allows users to fill in some general information about themselves so others get a better sense of who they are. They can fill in as little or as much as they wish. Users will need to open a message in order to access Introductions. If the person who wrote the message also has an Introduction, the Introduction button will appear in the list of buttons on the message.

Encourage the study participant to send an Introduction later (they can do it now, but it takes up a fair amount of time – so I suggest they do it later). Click on the Services button to return to the Services page.

f. Decisions and Planning Guides

Briefly go through Decisions, Decisions with the woman. Decisions, Decisions is broken up into three categories: Decision Workbook, Learning From Others, and Dept. of Defense Breast Cancer Decision Guide. Begin by going through Decision Workbook with the user.

There are two decision tools in the Decision Workbook available for women with breast cancer. They are:

- Choosing a Surgery
- Chemotherapy

The program contains step by step instructions of what to do. Each step describes the various options and discusses the concerns for each option. The users are asked to consider each option against the concerns, which other women with breast cancer felt were important. They may also want to type in their own options and concerns. At the end they will be taken to a summary screen which combines all the options with the concerns they felt were important.

Learning From Others is also a decision making tool. It is made up of various women telling their personal experiences with different aspects of their breast cancer experience. The women tell their stories using video and audio so the users can both see and hear them. Be sure to show the women how to use the video capabilities.

g. Health Tracking

In Health Tracking, the participant can choose which health issues she wants to keep track of over time.

Click on Health Tracking so she can see the list of items she can track. Choose from the three lists (Physical Health, Social/Emotional or Health Risks) several items that she would be interested in tracking. Explain that she can change the items she is tracking at any time. Just pick a couple of items right now and let her go back later and do as many other items as she is interested in.

Click Move On at the bottom of the screen. This will take her to the beginning of the questions the program will ask about each item she has chosen to track. Go through the questions with her. When she has finished, show her the graph and how she gets more information...

To get to the graph click on See graphs of how our items vary over time. You will get an explanation of what comes next. Press Move On to get to the graph. Choose one of the graphs to look at. Explain that as she tracks things over time, the graph will display the changes. Use the Back button on the browser to go back to the last menu. This time, go to the keyword, instead of the graph. You will then see a list of services that have information specific to that word. This works the same as any keyword. When you are finished, click on Services at the top left of the page to get back to the Services page.

Briefly touch on the rest of the services verbally with the woman as you finish up the explanation of CHESS. Remind her of the information in Getting Started which will go over each of the services and how they can be of use to her.

4. TRAINING FOR THOSE RECEIVING INTERNET ONLY

To begin training, click on the Internet browser icon on the desktop. The Gateway Home Page will come up as the Home Page for the browser. To begin:

- a. **Explain** the navigation functions of the browser:
 - **Back/Forward Button**
The BACK and FORWARD buttons are located on the browser toolbar at the left hand side of the screen. The BACK button allows the user to jump back to the previous screen you were viewing. The FORWARD button allows them to move forward in the same way.
 - **Scroll Bar**
Show the user how to move the screen up or down by either clicking on the bar with the left hand mouse button and dragging the mouse up or down or by using the arrows at the top or bottom of the screen.
 - **Home**
Explain to the user that this will always bring them back whatever they have chosen as their home page.
- b. **Highlight** the fact that when the cursor moves over a link, it changes from an arrow to a hand. This will help the user find links when they are in the form of pictures or other graphics.
- c. **Show** the user the way that a hyperlink changes color when they have already visited it.
- d. **Show** the user how to use the mouse and click into a search box in order to begin typing the words for the search.
- e. **Show** the user how to change their Home Page by changing it from Gateway to Alta Vista (www.altavista.com).
- f. **Demonstrate** how to use the search engine Alta Vista (www.altavista.com). Use the help section provided on the page to show the user different ways to search and then try searching for something they are interested in. A suggestion would be to have them search for "dogs", and then, to narrow the search, search for "police dogs." This will give them an idea of how many entries will can come up for a general topic, as well as how to narrow their search topic.

At the end of the training, highlight the information you will be leaving with them making sure they know they can refer to it if they have any questions, as well as for suggestions of good websites to visit.

5. TURNING OFF THE COMPUTER

Explain that when the user is finished using CHESS and wants to turn it off, she should first click the Exit button on the tool bar. This will return her to the "Welcome to CHESS" screen.

The user should then double click on the two attached computers down in the bottom right hand side of the screen. A box will appear called "Connected to CHESS Internet." She should click "Disconnect" in order to disconnect her computer from the Internet.

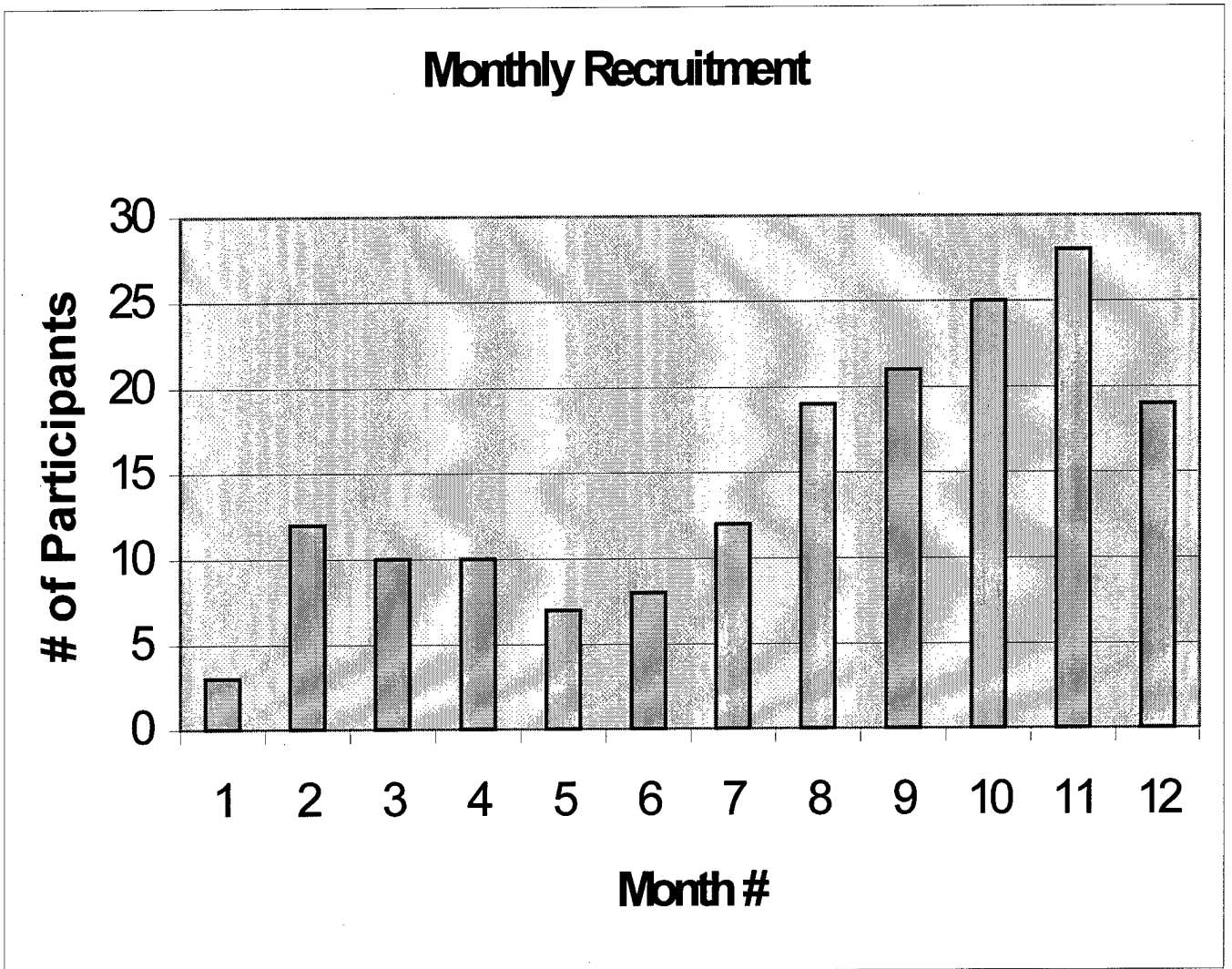
To turn off the computer she should click on the "Start" button on the lower left hand corner of the screen. Then she should click once on "Shut Down." Another message will pop up and she should choose "Yes" to shut down the computer.

At this point have the user start up the computer and log in using their own code name and password just to be sure that they know how to start it up. Once they get logged on, have them exit and turn off the computer.

6. OTHER INFORMATION

- a.** Ask the woman you are showing the computer to if she has any further questions.
- b.** Be sure that your name and number is written down on the instruction sheet in the folder. Reassure her that she can call you if she has any questions, needs any help, or is having trouble.
- c.** Tell them that you will give them a call in about a week in order to make sure everything is going okay.
- d.** If they have received CHESS, reiterate that you would like them to write a note in the open discussion group within the next few days in order make sure that their computer is working properly. They can write a real message or simply write "this is a test."
- e.** Thank them for their time!

Appendix # 2
Monthly Recruitment Rate Graph



Appendix # 3

CHESS Project:

Comprehensive Health Enhancement Support System

PreTest

If you have any questions please contact:

*Fiona McTavish
University of Wisconsin – Madison
Center for Health Systems Research and Analysis
1124 WARF Building
610 Walnut Street
Madison, WI 53705*

1-800-361-5481 or 1-608-262-7852

Fmctavish@chsra.wisc.edu

Code Number: _____

For this research on different kinds of assistance for women facing breast cancer, we need to have some idea how you're doing now, before the study starts. Below is a list of things that other women with breast cancer have said. By checking one box per line, please indicate how true each statement is for you.

<i>At this time...</i>	Not at all	A little bit	Some- what	Quite a bit	Very much
1. There are people I could count on for emotional support.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
2. There are people I could rely on when I need help doing something.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
3. There are people who will help me evaluate things I'm finding out about my illness.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
4. I am pretty much all alone.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
5. There are people who can help me find out the answers to my questions.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
6. There are people who will fill in for me if I am unable to do something.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4

Below is a list of statements concerning how you're dealing with breast cancer. By checking one box per line, please indicate how much you agree/disagree with each statement during the past 7 days. [CHECK ONE BOX ON EACH LINE]

	Disagree very much	Disagree	Neither agree or disagree	Agree	Agree very much
7. I needed more information about breast cancer from the perspective of patients who have been there.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
8. I needed more understandable information about breast cancer.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
9. I needed more information about the latest breast cancer research.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
10. I needed more contact with people who understood what I was going through.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
11. I needed help making decisions.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
12. I understood what my doctor told me.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
13. I was confident I could have a positive effect on my health.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
14. I set some definite goals to improve my health.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
15. I was generally able to accomplish my goals with respect to my health.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
16. I actively worked to improve my health.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
17. I felt that I was in control of how and what I learned about my health.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4

Below is a list of things that other women with breast cancer have said. By checking one box per line, please indicate how true each statement is for you.

At this time...

- | | Not at
all | A little
bit | Some-
what | Quite a
bit | Very
much |
|---|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| 18. I am able to work (including work in home). | ☐ 0 | ☐ 1 | ☐ 2 | ☐ 3 | ☐ 4 |
| 19. My work (including work in home) is fulfilling. | ☐ 0 | ☐ 1 | ☐ 2 | ☐ 3 | ☐ 4 |
| 20. I am able to enjoy life "in the moment". | ☐ 0 | ☐ 1 | ☐ 2 | ☐ 3 | ☐ 4 |
| 21. I am sleeping well. | ☐ 0 | ☐ 1 | ☐ 2 | ☐ 3 | ☐ 4 |
| 22. I am enjoying my usual leisure pursuits. | ☐ 0 | ☐ 1 | ☐ 2 | ☐ 3 | ☐ 4 |
| 23. I feel sad. | ☐ 0 | ☐ 1 | ☐ 2 | ☐ 3 | ☐ 4 |
| 24. I feel like my life is a failure. | ☐ 0 | ☐ 1 | ☐ 2 | ☐ 3 | ☐ 4 |
| 25. I feel nervous. | ☐ 0 | ☐ 1 | ☐ 2 | ☐ 3 | ☐ 4 |
| 26. I am worried about dying. | ☐ 0 | ☐ 1 | ☐ 2 | ☐ 3 | ☐ 4 |
| 27. I feel like everything is an effort. | ☐ 0 | ☐ 1 | ☐ 2 | ☐ 3 | ☐ 4 |
| 28. I am worried that my condition will get worse. | ☐ 0 | ☐ 1 | ☐ 2 | ☐ 3 | ☐ 4 |

Please indicate how true each statement is for you. [CHECK ONE BOX ON EACH LINE]

During the past 7 days:

- | | Does
not
apply | Not at
all | A little
bit | Some-
what | Quite a
bit | Very
much |
|---|-----------------------|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| 29. I was short of breath. | | ☐ 0 | ☐ 1 | ☐ 2 | ☐ 3 | ☐ 4 |
| 30. I was self-conscious about the way I dress. | | ☐ 0 | ☐ 1 | ☐ 2 | ☐ 3 | ☐ 4 |
| 31. I was bothered by swollen or tender arms. | | ☐ 0 | ☐ 1 | ☐ 2 | ☐ 3 | ☐ 4 |
| 32. I felt sexually attractive. | | ☐ 0 | ☐ 1 | ☐ 2 | ☐ 3 | ☐ 4 |
| 33. I worried about the risk of cancer in other family members. | ☐ | ☐ 0 | ☐ 1 | ☐ 2 | ☐ 3 | ☐ 4 |
| 34. I worried about the effect of stress on my illness. | | ☐ 0 | ☐ 1 | ☐ 2 | ☐ 3 | ☐ 4 |
| 35. My change in weight bothered me. | ☐ | ☐ 0 | ☐ 1 | ☐ 2 | ☐ 3 | ☐ 4 |
| 36. I was able to feel like a woman. | | ☐ 0 | ☐ 1 | ☐ 2 | ☐ 3 | ☐ 4 |

Thinking about your experiences since you've had breast cancer, how much do you agree or disagree with these statements? [CHECK ONE BOX ON EACH LINE]

	Disagree very much	Disagree	Neither Agree or Disagree	Agree	Agree very much
Since I've had breast cancer,					
37. Having information about my breast cancer, treatment, and prognosis gives me a sense of control.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
38. I prefer to have all the details (including possible risks) regarding my breast cancer and treatment options.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
39. I feel comfortable in asking the physician or nurse questions.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
40. I feel confident in making decisions about my health.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
41. I can figure out how and where to get the information I need.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
42. I know what questions to ask my doctor.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
43. I am able to be assertive with my doctor.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
44. I have confidence in my doctor.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4

How much do you agree or disagree with these statements? [CHECK ONE BOX ON EACH LINE]

	Disagree very much	Disagree	Neither Agree or Disagree	Agree	Agree very much
At this point I feel I understand:					
45. The effect my treatment will have on my quality of life.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
46. How to deal with breast cancer in my work and with my family.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
47. What my treatments will be like.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
48. The Pro's and Con's of various treatment approaches.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
49. How to know if a health care provider is good.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
50. How to get through my treatments and their side effects.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
51. How to get a second opinion if I want one.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4

Please tell us about yourself BEFORE you were diagnosed with breast cancer (even before you first noticed the symptom or had the test that raised the possibility of breast cancer). Try to remember how you were feeling then in answering the following question. . [CHECK ONE BOX]

52. In general, would you say you have been:

☐₁ Feeling normal with no complaints and able to carry on your usual activities.

☐₂ Performing normal activities with some effort and minor signs of illness.

☐₃ Unable to carry on your usual activities or do physical tasks. Requiring occasional assistance but in bed less than 50% of the daytime.

☐₄ Disabled, requiring special care and assistance in most activities & in bed more than 50% of the daytime, but not all day.

☐₅ Very sick, hospitalized for some time or in bed all of the time.

Appendix # 4

CHES Project:

Comprehensive Health Enhancement Support System

2-Week Post Test

(The 4 and 6 week survey are duplicates of the 2 week survey)

If you have any questions please contact:

*Fiona McTavish
University of Wisconsin – Madison
Center for Health Systems Research and Analysis
1124 WARF Building
610 Walnut Street
Madison, WI 53705*

1-800-361-5481 or 1-608-262-7852

Fmctavish@chsra.wisc.edu

Code Number: _____

TREATMENT DECISIONS

1. *Check the box that best describes how you would like to make important treatment decisions:*
[CHECK ONLY ONE BOX]

- ☐₁ I prefer to make the decision about my treatment myself
- ☐₂ I prefer to make the final decision about my treatment after seriously considering my doctor's opinion
- ☐₃ I prefer that my doctor & I share responsibility for deciding which treatment is best for me.
- ☐₄ I prefer that my doctor make the final decision about which treatment will be used but seriously consider my opinion.
- ☐₅ I prefer to leave all decisions regarding treatment to my doctor.

2. *Please indicate if, during the last two weeks, you have considered whether or not to have any of the following treatments.*

In the last 2 weeks I considered... [CHECK ALL THAT APPLY]

- ☐₁ Fine needle biopsy
- ☐₂ Lumpectomy versus mastectomy
- ☐₃ What to radiate (e.g., axillary *or underarm* lymph nodes)
- ☐₄ Breast reconstruction
- ☐₅ Type of reconstruction
- ☐₆ Timing of reconstruction
- ☐₇ Lymph node sampling
- ☐₈ How many lymph nodes to sample
- ☐₉ Chemotherapy
- ☐₁₀ Type of chemotherapy
- ☐₁₁ Length of chemotherapy
- ☐₁₂ Bone marrow transplant
- ☐₁₃ Oophorectomy (ovary removal)
- ☐₁₄ Tamoxifen
- ☐₁₅ Clinical trial participation
- ☐₁₆ Immunotherapy
- ☐₁₇ Alternative treatments
- ☐₁₈ Stopping treatment
- ☐₁₉ Other, please specify: _____

3. *Of the decisions that you checked above, what one was the most important to you?*

*If you did **not** check any of the decisions above, check here ☐ and go to the top of page 3.*

Thinking about the most important treatment decision you considered, please indicate how much you agree/disagree with the following statements. [CHECK ONE BOX PER LINE]

	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
1. It is difficult to make a choice.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
2. It's clear what choice is best for me.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
3. I'm aware of the choices I have in making this decision.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
4. I know the relative benefits of my options for this decision.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
5. I know the relative risks and side effects of my options for this decision.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
6. The information I have to make this decision is easy to understand.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
7. I have no problem using the information I have in making this decision.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
8. Consulting someone else would have been useful in making this decision.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
9. I am satisfied that I am adequately informed about the issues important to my decision.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
10. I need more advice and information about my options.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
11. I have access to information on all my options.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

If you have decided what to do for this decision at this point, please indicate how much you agree/disagree with the following statements. Otherwise please go to the beginning of page 3.

	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
1. My treatment choice is sound.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
2. I am satisfied with my treatment choice.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
3. My treatment choice is the right one for my situation.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
4. I am satisfied that my treatment choice was consistent with my personal values.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
5. I feel I have made an informed choice.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

NON-TREATMENT DECISIONS

1. Please indicate whether you have **considered** any of the following **non-treatment decisions** in the last two weeks.

I considered... [CHECK ALL THAT APPLY]

- | | |
|--|---|
| ☐ ₁ Whether to change doctors? | ☐ ₆ Whether to go to a support group? |
| ☐ ₂ Whether to seek second opinion? | ☐ ₇ Whether to quit smoking? |
| ☐ ₃ Who/what to tell family/friends/
children/co-workers? | ☐ ₈ Whether to leave my partner? |
| ☐ ₄ Who to be around? | ☐ ₉ End of life decisions? |
| ☐ ₅ Whether to quit work/go back to work? | ☐ ₁₀ Other, please specify: _____ |

2. Of the **non-treatment decisions** that you checked above, what one was the most important to you?

*If you did **not** check any of the decisions above, check here ☐ and go to question 6 on the following page.*

*Thinking about that most important **non-treatment** decision that you **considered**, please indicate how much you agree/disagree with the following statements. [CHECK ONE BOX ON EACH LINE]*

	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
1. It is difficult for me to make a choice.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
2. It's clear what choice is best for me.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
3. I'm aware of the choices I have in making this decision.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
4. I feel I know the relative benefits and risks of my options for this decision.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
5. Consulting someone else would be useful in making this decision.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
6. I am satisfied that I am adequately informed about the issues important to my decision.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
7. I need more advice and information about my options.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
8. I have access to information on all my options.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
9. I have the right amount of support from others in making this decision.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

If you have **decided** what to do for this ***non-treatment decision*** at this point, please indicate how much you agree/disagree with the following statements. [CHECK ONE BOX ON EACH LINE]

	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
1. My decision is sound.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
2. I am satisfied with my decision.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
3. My decision is the right one for my situation.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
4. I am satisfied that my decision was consistent with my personal values.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
5. I feel I have made an informed choice.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
6. Today's date: _____					

Thank you for completing this questionnaire. Please mail it back in the envelope provided. If you have any question please call 1-800-361-5481. Thanks again!

Appendix # 5

CHESS Project:

Comprehensive Health Enhancement Support System

**2-Month Post Test
CHESS**

If you have any questions please contact:

*Fiona McTavish
University of Wisconsin – Madison
Center for Health Systems Research and Analysis
1124 WARF Building
610 Walnut Street
Madison, WI 53705*

1-800-361-5481 or 1-608-262-7852

Fmctavish@chsra.wisc.edu

Code Number: _____

Below is a list of statements that women with breast cancer have said about the information and support they have received from others. We would like to know about your experiences. Please indicate how frequently each of the following statements are true for you. [CHECK ONE BOX PER LINE]

At this time ...

	Never	Rarely	Some- times	Often	Always
1. I can get answers to my questions at any time.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
2. I can easily get the information I need.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
3. I can get information from other women who have had breast cancer.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
4. Whenever I worry, there is someone I can go to.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
5. I am building a bond with other women with breast cancer.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
6. I feel stronger knowing there are others in my situation.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
7. I've been getting emotional support from others in my situation.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
8. It helps me to be able to share my feelings and fears.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
9. I get practical, concrete advice on how to go through my treatment.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
10. There is no one I can turn to for help when I need it.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
11. Someone steps in if there are everyday things I can't do because of my illness.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
12. I feel comfortable discussing my cancer with others.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4

Please indicate how frequently each of the following statements are true for you:
[CHECK ONE BOX PER LINE]

At this time ...	Never	Rarely	Some- times	Often	Always
1. The help I have received has reduced the burden on my family.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
2. I have enough information to help my daughter(s).	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
3. My family does not support me.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
4. I have the help I need to go on with my life.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
5. I feel as though I have the strength to deal with my breast cancer.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
6. The information and support I received helped reduce my fear of cancer.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
7. I am not afraid to walk away from treatment if it seems right to me.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
8. I am able to understand statistics about breast cancer treatment.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
9. The information and support I have received have made me less anxious.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
10. I know exactly what it is that I want to learn about my health.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
11. I can figure out how and where to get the information I need.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
12. Health information is more difficult for me to obtain than other types of information.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
13. I am satisfied with the way I currently learn about health issues.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
14. I feel that I am in control over how and what I learn about my health.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4

How much do you agree or disagree with the following statements? . [CHECK ONE BOX PER LINE]

At this time I feel I understand ...	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
1. The effect my treatment will have on my quality of life.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
2. How to deal with breast cancer in my work and with my family.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
3. What my treatments will be like.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
4. The Pro's and Con's of various treatment approaches.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
5. How to know if a health care provider is good.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
6. How to get through my treatments and their side effects.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
7. How to get a second opinion if I want one.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
8. What the side effects of my treatment would be, before I started.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4

Please indicate how frequently each of the following statements are true for you: [CHECK ONE BOX PER LINE]

At this time...	Never	Rarely	Sometimes	Often	Always
1. Having information about my breast cancer, treatment, and prognosis gives me a sense of control.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
2. I prefer to have all the details (including possible risks) regarding my breast cancer and treatment options.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
3. I feel comfortable in asking the physician or nurse questions.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
4. I feel confident in making decisions about my health.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
5. I know what questions to ask my doctor.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
6. I am able to be assertive with my doctor.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
7. I have confidence in my doctor.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
8. I am comfortable discussing my treatment options with my doctor.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
9. I can manage my own care and be sure that the right treatment is given.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4

For this research on how to help women facing breast cancer, we need to have some idea how you're doing now. Below is a list of things that other women with breast cancer have said. Please indicate how true each statement is for you. [CHECK ONE BOX PER LINE]

At this time ...	Not at all	A little bit	Some-what	Quite a bit	Very much
1. There are people I could count on for emotional support.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
2. There are people who will help me evaluate things I'm finding out about my illness.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
3. I am pretty much all alone.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
4. There are people I could rely on when I need help doing something.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
5. There are people who can help me find out the answers to my questions.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
6. There are people who will fill in for me if I am unable to do something.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
7. I am able to work (including work in home).	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
8. My work (including work in home) is fulfilling.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
9. I am able to enjoy life "in the moment".	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
10. I am sleeping well.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
11. I am enjoying my usual leisure pursuits.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
12. I feel sad.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
13. I feel like my life is a failure.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
14. I feel nervous.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
15. I am worried about dying.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
16. I feel like everything is an effort.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
17. I am worried that my illness will get worse.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4

Below is a list of statements concerning how you're dealing with breast cancer. Please indicate how much you agree/disagree with each statement. [CHECK ONE BOX PER LINE]

In the past 7 days...	Disagree very much	Disagree	Neither agree nor disagree	Agree	Agree very much
1. I needed more information about breast cancer from the perspective of patients who have been there.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
2. I needed more understandable information about breast cancer.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
3. I needed more information about the latest breast cancer research.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
4. I needed more contact with people who understood what I was going through.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
5. I needed help making decisions.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
6. I understood what my doctor told me.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
7. I was confident that I could have a positive effect on my health.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
8. I set some definite goals to improve my health.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
9. I actively worked to improve my health.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4

Below is a list of statements concerning the amount of information about breast cancer you feel you need. Please indicate how true each statement has been for you.. [CHECK ONE BOX PER LINE]

In the past 7 days...	Disagree very much	Disagree	Neither agree nor disagree	Agree	Agree very much
1. I wanted health information that I didn't know how to get.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
2. I needed health information that I couldn't afford the time or effort to get.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
3. I needed health information that I couldn't afford to pay for.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4

Please indicate how true each statement is for you. [CHECK ONE BOX PER LINE]

During the past 7 days...

	Does not apply	Not at all	A little bit	Some- what	Quite a bit	Very much
1. I was short of breath.		☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
2. I was self-conscious about the way I dress.		☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
3. I was bothered by swollen or tender arms.		☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
4. I felt sexually attractive.		☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
5. I worried about the risk of cancer in other family members.	☐	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
6. I worried about the effect of stress on my illness.		☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
7. My change in weight bothered me.	☐	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
8. My hair loss bothered me.	☐	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
9. I am able to feel like a woman.		☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
10. My skin bothered me as a result of radiation treatment.	☐	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
11. I was fatigued.		☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄

For the question below, please check the box which best describes how you have been feeling in the last week. In general, would you say you have been: [CHECK ONLY ONE BOX]

- ☐₁ Feeling normal with no complaints and able to carry on your usual activities
- ☐₂ Performing normal activities with some effort and minor signs of illness
- ☐₃ Unable to carry on your usual activities or do physical tasks. Requiring occasional assistance but in bed less than 50% of the daytime
- ☐₄ Disabled, requiring special care and assistance in most activities and in bed more than 50% of the daytime, but not all day
- ☐₅ Very sick, hospitalized for some time or in bed all of the time

Please check how much you agree or disagree with the following statements [CHECK ONE BOX PER LINE]

	Disagree very much	Disagree	Neither Agree nor Disagree	Agree	Agree very much
During the past 7 days...					
1. It was difficult for me to find effective solutions for health problems that came my way.	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
2. I handled myself well with respect to my health.	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
3. I succeeded in the projects I undertook to improve my health.	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
4. I was generally able to accomplish my goals with respect to my health.	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
5. I found the efforts to change things I didn't like about my health were ineffective.	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
6. I was able to do things for my health as well as most other people.	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
In general...					
7. My plans for my health don't work out well.	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
8. No matter how hard I try, my health doesn't turn out the way I would like.	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄

The items below deal with ways you have been coping with the stress in your life since you found out you have breast cancer. Different people deal with stress in different ways. We are interested in how you have tried to deal with stress. Don't answer on the basis of whether or not it seems to be working or not – just whether or not you're doing it. [CHECK ONE BOX PER LINE]

In the past 2 weeks ...	I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
1. I've been turning to work or other activities to take my mind off things.	☐ ₁	☐ ₂	☐ ₃	☐ ₄
2. I've been trying to see breast cancer in a different light, to make it seem more positive.	☐ ₁	☐ ₂	☐ ₃	☐ ₄
3. I've been criticizing myself.	☐ ₁	☐ ₂	☐ ₃	☐ ₄
4. I've been looking for something good in what is happening.	☐ ₁	☐ ₂	☐ ₃	☐ ₄
5. I've been making jokes about breast cancer.	☐ ₁	☐ ₂	☐ ₃	☐ ₄
6. I've been doing something to think about breast cancer less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.	☐ ₁	☐ ₂	☐ ₃	☐ ₄
7. I've been trying to find comfort in my religion or spiritual beliefs.	☐ ₁	☐ ₂	☐ ₃	☐ ₄
8. I've been blaming myself for things that happened.	☐ ₁	☐ ₂	☐ ₃	☐ ₄
9. I've been praying or meditating.	☐ ₁	☐ ₂	☐ ₃	☐ ₄
10. I've been making fun of the situation.	☐ ₁	☐ ₂	☐ ₃	☐ ₄
11. I have been helping other women with breast cancer.	☐ ₁	☐ ₂	☐ ₃	☐ ₄

TREATMENT DECISIONS

1. Check the box that best describes how you would like to make important treatment decisions:

[CHECK ONLY ONE BOX]

- ☐₁ I prefer to make the decision about my treatment myself
- ☐₂ I prefer to make the final decision about my treatment after seriously considering my doctor's opinion
- ☐₃ I prefer that my doctor & I share responsibility for deciding which treatment is best for me.
- ☐₄ I prefer that my doctor make the final decision about which treatment will be used but seriously consider my opinion.
- ☐₅ I prefer to leave all decisions regarding treatment to my doctor.

2. Please indicate if, during the last two weeks, you (and/or your doctors) have considered whether or not to have any of the following treatments.

In the last 2 weeks I considered... [CHECK ALL THAT APPLY]

- ☐₁ Fine needle biopsy
- ☐₂ Lumpectomy versus mastectomy
- ☐₃ What to radiate (e.g., axillary *or* underarm lymph nodes)
- ☐₄ Breast reconstruction
- ☐₅ Type of reconstruction
- ☐₆ Timing of reconstruction
- ☐₇ Lymph node sampling
- ☐₈ How many lymph nodes to sample
- ☐₉ Chemotherapy
- ☐₁₀ Type of chemotherapy
- ☐₁₁ Length of chemotherapy
- ☐₁₂ Bone marrow transplant
- ☐₁₃ Oophorectomy (ovary removal)
- ☐₁₄ Tamoxifen
- ☐₁₅ Clinical trial participation
- ☐₁₆ Immunotherapy
- ☐₁₇ Alternative treatments
- ☐₁₈ Stopping treatment
- ☐₁₉ Other, please specify: _____

3. Of the decisions that you checked above, what one was the most important to you? _____
- If you did **not** check any of the decisions above, check here ☐ and go to the top of page 11.

Thinking about the most important treatment decision you considered, please indicate how much you agree/disagree with the following statements. [CHECK ONE BOX PER LINE]

	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
1. It is difficult to make a choice.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
2. It's clear what choice is best for me.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
3. I'm aware of the choices I have in making this decision.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
4. I know the relative benefits of my options for this decision.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
5. I know the relative risks and side effects of my options for this decision.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
6. The information I have to make this decision is easy to understand.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
7. I have no problem using the information I have in making this decision.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
8. Consulting someone else would have been useful in making this decision.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
9. I am satisfied that I am adequately informed about the issues important to my decision.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
10. I need more advice and information about my options.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
11. I have access to information on all my options.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

If you have decided what to do for this decision at this point, please indicate how much you agree/disagree with the following statements. Otherwise please go to the beginning of page 11.

	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
1. My treatment choice is sound.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
2. I am satisfied with my treatment choice.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
3. My treatment choice is the right one for my situation.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
4. I am satisfied that my treatment choice was consistent with my personal values.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
5. I feel I have made an informed choice.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

NON-TREATMENT DECISIONS

1. Please indicate whether you have **considered** any of the following **non-treatment decisions** in the last two weeks.

I considered... [CHECK ALL THAT APPLY]

- | | |
|--|---|
| ☐ ₁ Whether to change doctors? | ☐ ₆ Whether to go to a support group? |
| ☐ ₂ Whether to seek second opinion? | ☐ ₇ Whether to quit smoking? |
| ☐ ₃ Who/what to tell family/friends/
children/co-workers? | ☐ ₈ Whether to leave my partner? |
| ☐ ₄ Who to be around? | ☐ ₉ End of life decisions? |
| ☐ ₅ Whether to quit work/go back to work? | ☐ ₁₀ Other, please specify: _____ |

2. Of the **non-treatment decisions** that you checked above, what one was the most important to you?

_____ If you did **not** check any of the decisions above, check here ☐ and go to question 1 on the middle of page 12.

Thinking about that most important **non-treatment decision** that you **considered**, please indicate how much you agree/disagree with the following statements. [CHECK ONE BOX ON EACH LINE]

	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
1. It is difficult for me to make a choice.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
2. It's clear what choice is best for me.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
3. I'm aware of the choices I have in making this decision.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
4. I feel I know the relative benefits and risks of my options for this decision.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
5. Consulting someone else would be useful in making this decision.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
6. I am satisfied that I am adequately informed about the issues important to my decision.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
7. I need more advice and information about my options.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
8. I have access to information on all my options.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
9. I have the right amount of support from others in making this decision.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

If you have **decided** what to do for this **non-treatment decision** at this point, please indicate how much you agree/disagree with the following statements. [CHECK ONE BOX ON EACH LINE].

(If you have not decided what to do for this non-treatment decision, please skip the next five questions and go to question 1 in the middle of this page).

	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
10. My decision is sound.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
11. I am satisfied with my decision.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
12. My decision is the right one for my situation.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
13. I am satisfied that my decision was consistent with my personal values.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
14. I feel I have made an informed choice.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

For each of the following questions, please check the box for the answer that comes closest to the way you have been feeling during the past month. [CHECK ONE BOX PER LINE]

"Because of breast cancer, during the past month I felt ..."

	Never	Rarely	Sometimes	Often	Always
1. Helpless	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
2. Tense	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
3. Loved/Cared for	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
4. Angry	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
5. Hopeless	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
6. Worried	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
7. Supported	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
8. Frustrated	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
9. Sad	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
10. Anxious	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Use the table below to describe your **in-person visits over the last two months** to various health care providers. In each row is a different kind of health care provider, and the columns are number of visits, length of visit, and overall satisfaction. If you haven't used a certain kind of health care provider in the last two months, leave the whole row blank. We've filled in a sample in the first row to show you how someone might answer. Do not include the time you may have spent overnight in the hospital or for day surgeries in this table. Hospitalizations and surgeries will be covered on the following page.

IN-PERSON VISITS TO HEALTH CARE PROVIDERS

	Number of times your visited in the last 2 months	Average amount of time you spent with providers (specify minutes or hours)*	Overall, how satisfied were you with visits to this provider? (Use a 1 to 5 scale, 1=very dissatisfied to 5=very satisfied)
Example	2 visits	30 minutes	4
Primary Doctor (e.g. Internist) - NOT Breast Cancer Specialist			
Surgeon			
Plastic Surgeon			
Radiologist			
Oncologist			
Mental Health Provider (e.g. psychologist, counselor, therapist)			
Other Specialty Clinic (dermatologist, etc.)			
Outpatient Lab Visit (e.g. blood test, x-ray, etc.)			
Emergency Room			
Non-Medical Doctor Office (e.g. osteopath, chiropractor)			
Dental Clinic (dentist, oral surgeon, etc.)			
Alternative Care Provider (e.g. massage, acupuncture, etc.)			
Telephone consultations			

*Include time spent with all provider staff (doctors, nurses, pharmacists, etc.)

Use the table below to describe your **hospital visits (either overnight stays or day surgeries)** over the last two months. In the first column is the type of care (day surgery, overnight hospital stays). The next column asks for reason for stay (such as mastectomy, etc). Then fill in length of stays (# hours or days), and finally your overall satisfaction with the care you received. **If you have not had any day surgeries or overnight hospital stays in the last 2 months skip to question #1 on this same page.**

OVERNIGHT HOSPITAL VISITS AND DAY SURGERIES

DURING THE LAST 2 MONTHS...	Reasons for day surgery or overnight hospitalization (e.g. lumpectomy, mastectomy...)	Number of hours (if day surgery), or number of days (if overnight stays)	Overall, how satisfied were you with your care? (Use a 1 to 5 scale, 1=very dissatisfied to 5=very satisfied)
Day Surgery (not overnight stays)			
Overnight Hospital Stays			

Think about **all your health care during the past two months** (doctors, dentists, hospitals, therapists, emergency rooms). Mark whether you agree or disagree with the following statements. [CHECK ONE BOX PER LINE]

In the past 2 months...	Disagree very much	Disagree	Neither Agree nor Disagree	Agree	Agree very much
1. I thought about what was going to happen ahead of time.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
2. I felt comfortable with how actively I participated in my care	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4

Please answer the following questions:

3. Today's date: _____

4. Your age: _____

5. Racial/Ethnic Heritage:

☐ 1 African American

☐ 3 Caucasian

☐ 5 Native American Indian

☐ 2 Asian

☐ 4 Latina/Mexican American

☐ 6 Other _____

6. *What type of health insurance coverage do you have (include coverage obtained through a spouse or relative)?* [CHECK ALL THAT APPLY]

- ☐₁ Private group insurance (through you/spouse's employer, union or trade group)
- ☐₂ Individual policy
- ☐₃ Medicaid (also called Title 19 or Medical Assistance)
- ☐₄ Medicare, Part A (pays for hospital bills)
- ☐₅ Medicare, Part B (pays for doctor's bills)
- ☐₆ Medigap policy (supplementary private insurance to Medicare)
- ☐₇ CHAMPUS or CHAMPVA
- ☐₈ Other: _____
- ☐₉ No insurance

7. *Please indicate the highest education level that you have completed.* [CHECK ONE BOX]

- ☐₁ Some junior high/middle school
- ☐₂ Some high school
- ☐₃ High School degree
- ☐₄ Some college courses
- ☐₅ Associate or Technical degree (2 year college)
- ☐₆ Bachelor's degree (4 year college)
- ☐₇ Graduate degree

8. *With whom do you currently live?* [CHECK ALL THAT APPLY].

- ☐₁ I live by myself
- ☐₂ I live with my partner (husband, lover)
- ☐₃ I live with one or more dependent children,
Please list ages and sex of dependent children _____
- ☐₄ I live with one or both of my parents
- ☐₅ I live with other family members
- ☐₆ I live with a friend or friends
- ☐₇ Other, please specify _____

9. *What was your total household income from all sources last year?* [CHECK ONE BOX]

- ☐₁ Less than \$10,000
- ☐₂ \$10,000 - \$19,999
- ☐₃ \$20,000 - \$39,999
- ☐₄ \$40,000 - \$59,999
- ☐₅ \$60,000 or more

10. *When was your breast cancer first diagnosed (give approximate date):* _____

11. *Has your breast cancer spread (metastasized) to other parts of your body other than your lymph nodes?*

- ☐₀ No
- ☐₁ Yes, when did you learn this (give approximate date): _____

12. *Have you had a recurrence of your breast cancer?*

☐₀ No

☐₁ Yes, when did you learn this (give approximate date): _____

13. *What is the stage of your cancer?*

☐₀ Stage 0

☐₁ Stage 1

☐₂ Stage 2

☐₃ Stage 3

☐₄ Stage 4

☐₅ Inflammatory

☐₆ Don't Know

☐₇ Other _____

14. Do you have any other major illnesses or conditions (e.g., diabetes, high blood pressure, heart disease, extremely overweight, history of other cancer, etc.)?

☐₀ No

☐₁ Yes, please list your other major illnesses or conditions:

15. *What is your menopausal status?*

☐₁ Pre-Menopausal

☐₂ Peri-Menopausal

☐₃ Post-Menopausal

16. Write in the actual or scheduled dates for surgeries that you have completed, and those that you have scheduled. Also mark any other surgeries you are considering.

	Start Date (give approximate date):	Considering
• Radical mastectomy	_____	☐
• Modified radical mastectomy	_____	☐
• Lumpectomy	_____	☐
• Breast reconstruction	_____	☐
• Oophorectomy (ovary removal)	_____	☐
• Prophylactic (preventive) mastectomy of unaffected breast:	_____	☐
• Other _____	_____	☐

17. For each of the following breast cancer treatments, give the approximate starting and ending dates, or mark the box if you are seriously considering it. Give dates if you have done it, are doing it, or are planning a treatment.

	Start Date (give approximate dates):	End Date	Considering
• Chemotherapy	_____	_____	☐
• Radiation	_____	_____	☐
• Hormone Therapy (Tamoxifen, Halotestin)	_____	_____	☐
• High Dose Chemo or Bone Marrow Transplant	_____	_____	☐
• Other _____	_____	_____	☐

18. In addition to your prescribed treatments, what else are you doing for your breast cancer (diet, homeopathy, acupuncture, therapeutic touch, etc.)? Please list below:

In the last two months how **EASY WAS IT FOR YOU TO GET** information about breast cancer from the following: [CHECK ONE BOX PER LINE]

	VERY DIFFICULT	DIFFICULT	NEITHER EASY NOR DIFFICULT	EASY	VERY EASY
10A Books or articles	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
10B Audio or video tapes	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
10C Doctors or nurses	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
10D Other Patients	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
10E Family or friends	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
10F The Internet	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
10G CHESS	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

In the last two months **HOW MUCH DID YOU USE** the following resources to get information about breast cancer? [CHECK ONE BOX PER LINE]

	NOT AT ALL	ONCE OR TWICE	ATLEAST ONCE A MONTH	WEEKLY	ALMOST EVERY DAY	EVERY DAY
11A Books or articles	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
11B Audio or video tapes	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
11C Doctors or nurses	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
11D Other Patients	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
11E Family or friends	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
11F The Internet	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
11G CHESS	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

HOW USEFUL were each of the following in regards to information about breast cancer?
[CHECK ONE BOX PER LINE]

	NOT AT ALL	VERY LITTLE	LITTLE	SOME	A LOT	A GREAT DEAL
12A Books or articles	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
12B Audio or video tapes	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
12C Doctors or nurses	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
12D Other Patients	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
12E Family or friends	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
12F The Internet	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
12G CHESS	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

In the last two months **HOW USEFUL** were each of the following in terms of **MAKING A DECISION** in regards to breast cancer? [CHECK ONE BOX PER LINE]

	NOT AT ALL	VERY LITTLE	LITTLE	SOME	A LOT	A GREAT DEAL
13A Books or articles	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
13B Audio or video tapes	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
13C Doctors or nurses	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
13D Other Patients	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
13E Family or friends	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
13F The Internet	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
13G CHESS	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Please rate how **USEFUL** each of the following resources was in getting **EMOTIONAL SUPPORT**.

[CHECK ONE BOX PER LINE]

	NOT AT ALL	VERY LITTLE	LITTLE	SOME	A LOT	A GREAT DEAL
14A Books or articles	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
14B Audio or video tapes	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
14C Doctors or nurses	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
14D Other Patients	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
14E Family or friends	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
14F The Internet	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
14G CHESS	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

In the last two months **HOW MUCH HAVE YOU USED** the following resources to help you get **EMOTIONAL SUPPORT**? [CHECK ONE BOX PER LINE]

	NOT AT ALL	ONCE OR TWICE	AT LEAST ONCE A MONTH	WEEKLY	ALMOST EVERY DAY	EVERY DAY
15A Books or articles	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
15B Audio or video tapes	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
15C Doctors or nurses	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
15D Other Patients	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
15E Family or friends	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
15F The Internet	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
15G CHESS	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

We have included a picture of the CHESSE Services Menu in order to refresh your memory about the various services in CHESSE. Please indicate how helpful each of the following CHESSE services are to you.

Overall, how useful are each of the following CHESSE services? [CHECK ONE BOX PER LINE]

	Not at all	A little bit	Some- what	Quite a bit	Very much
1 Overview of Breast Cancer	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
<u>Decision and Planning Guide</u>					
2 Decisions Notebook (within Decisions, Decisions)	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
3 Learning from others (within Decisions, Decisions)	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
4 Action Plan	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
5 Consumer Guide	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
6 Resource Directory	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
<u>Personal Space</u>					
7 Health Tracking	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
8 Assessments	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
9 Journaling	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
<u>What's New</u>					
10 CHESSE News	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
11 News Items	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
<u>Reading Room</u>					
12 Questions and Answers	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
13 Instant Library	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄

Overall, how useful are each of the following CHESS services? [CHECK ONE BOX PER LINE]

	Not at all	A little bit	Some- what	Quite a bit	Very much
<u>Other Sites</u>					
14 Web Links	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
15 Medline	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
16 Evaluating Web Info	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
<u>Connecting with Others</u>					
17 Personal Stories	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
18 Discussion Group	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
19 Ask an Expert	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
20 Video Gallery	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
<u>Beginner's Guide</u>					
21 Basic Web Skills	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
22 Getting Started	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
23 About CHESS	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄

- How much does UNDERSTANDING YOUR SITUATION affect your ability to cope with breast cancer?
Not at all ☐₀ ☐₁ ☐₂ ☐₃ ☐₄ ☐₅ ☐₆ ☐₇ ☐₈ ☐₉ ☐₁₀ Very much so
- Overall, how much has CHESS helped you to cope with breast cancer?
Not at all ☐₀ ☐₁ ☐₂ ☐₃ ☐₄ ☐₅ ☐₆ ☐₇ ☐₈ ☐₉ ☐₁₀ Very much so
- Overall, how much has CHESS helped you in your decision making in regards to breast cancer?
Not at all ☐₀ ☐₁ ☐₂ ☐₃ ☐₄ ☐₅ ☐₆ ☐₇ ☐₈ ☐₉ ☐₁₀ Very much so

How much do you like each of the following characteristics of CHESS? [CHECK ONE BOX PER LINE]

	Not at all	A little bit	Some- what	Quite a bit	Very much
1 I can get information	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
2 I can analyze situations	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
3 I can communicate with others	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
4 The information is up to date	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
5 The information is trustworthy	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
6 I can find information easily	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
7 I got frustrated by how long it took for the information to appear on the screen (download time)	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄

How much do you like each of the following characteristics of the **Internet**? [CHECK ONE BOX PER LINE]

		Not at all	A little bit	Some- what	Quite a bit	Very much
1	I can get information	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
2	I can analyze situations	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
3	I can communicate with others	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
4	The information is up to date	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
5	The information is trustworthy	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
6	I can find information easily	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
7	I got frustrated by how long it took for the information to appear on the screen (download time)	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄

1 What do you like MOST about CHESS?

2 What do you like LEAST about CHESS?

3 How has CHESS helped you deal with your breast cancer?

4 How has CHESS changed your use of health care services?

5 What difference has CHESS made?

6 What else should CHESS have in it?

7 What were the things that interfered with or prevented you from using CHESS more?

8 What else would you like to tell us?

Thank you very much for taking the time to fill out this survey. Please mail it back in the self addressed stamped envelope provided with this survey. If you have any questions feel free to call 1-800-361-5481.

Appendix # 6

CHESS Project:

Comprehensive Health Enhancement Support System

4-Month Post Test CHESS

If you have any questions please contact:

*Fiona McTavish
University of Wisconsin – Madison
Center for Health Systems Research and Analysis
1124 WARF Building
610 Walnut Street
Madison, WI 53705*

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Code Number: _____

Below is a list of statements that women with breast cancer have said about the information and support they have received from others. We would like to know about your experiences. Please indicate how frequently each of the following statements are true for you: [CHECK ONE BOX PER LINE]

At this time ...	Never	Rarely	Sometimes	Often	Always
1. I can get answers to my questions at any time.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
2. I can easily get the information I need.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
3. I can get information from other women who have had breast cancer.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
4. Whenever I worry, there is someone I can go to.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
5. I am building a bond with other women with breast cancer.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
6. I feel stronger knowing there are others in my situation.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
7. I've been getting emotional support from others in my situation.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
8. It helps me to be able to share my feelings and fears.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
9. I get practical, concrete advice on how to go through my treatment.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
10. There is no one I can turn to for help when I need it.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
11. Someone steps in if there are everyday things I can't do because of my illness.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
12. I feel comfortable discussing my cancer with others.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4

The next list of statements covers the amount of information about breast cancer you feel you need. Please indicate how true each statement has been for you. [CHECK ONE BOX PER LINE]

In the past 7 days ...	Disagree very much	Disagree	Neither agree nor disagree	Agree	Agree very much
1. I wanted health information that I didn't know how to get.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
2. I needed health information that I couldn't afford the time or effort to get.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
3. I needed health information that I couldn't afford to pay for.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4

Please indicate how frequently each of the following statements are true for you:
[CHECK ONE BOX PER LINE]

At this time ...	Never	Rarely	Sometimes	Often	Always
1. The help I have received has reduced the burden on my family.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
2. I have enough information to help my daughter(s).	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
3. My family does not support me.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
4. I have the help I need to go on with my life.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
5. I feel as though I have the strength to deal with my breast cancer.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
6. The information and support I received helped reduce my fear of cancer.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
7. I am not afraid to walk away from treatment if it seems right to me.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
8. I am able to understand statistics about breast cancer treatment.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
9. The information and support I have received have made me less anxious.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
10. I know exactly what it is that I want to learn about my health.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
11. I can figure out how and where to get the information I need.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
12. Health information is more difficult for me to obtain than other types of information.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
13. I am satisfied with the way I currently learn about health issues.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
14. I feel that I am in control over how and what I learn about my health.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4

How much do you agree or disagree with the following statements? . [CHECK ONE BOX PER LINE]

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
At this time I feel I understand ...					
1. The effect my treatment will have on my quality of life.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
2. How to deal with breast cancer in my work and with my family.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
3. What my treatments will be like.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
4. The Pro's and Con's of various treatment approaches.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
5. How to know if a health care provider is good.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
6. How to get through my treatments and their side effects.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
7. How to get a second opinion if I want one.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
8. What the side effects of my treatment would be, before I started.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4

Please indicate how frequently each of the following statements are true for you: [CHECK ONE BOX PER LINE]

At this time...	Never	Rarely	Some- times	Often	Always
1. Having information about my breast cancer, treatment, and prognosis gives me a sense of control.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
2. I prefer to have all the details (including possible risks) regarding my breast cancer and treatment options.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
3. I feel comfortable in asking the physician or nurse questions.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
4. I feel confident in making decisions about my health.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
5. I know what questions to ask my doctor.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
6. I am able to be assertive with my doctor.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
7. I have confidence in my doctor.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
8. I am comfortable discussing my treatment options with my doctor.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
9. I can manage my own care and be sure that the right treatment is given.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4

For this research on how to help women facing breast cancer, we need to have some idea how you're doing now. Below is a list of things that other women with breast cancer have said. Please indicate how true each statement is for you. [CHECK ONE BOX PER LINE]

At this time ...	Not at all	A little bit	Some-what	Quite a bit	Very much
1. There are people I could count on for emotional support.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
2. There are people who will help me evaluate things I'm finding out about my illness.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
3. I am pretty much all alone.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
4. There are people I could rely on when I need help doing something.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
5. There are people who can help me find out the answers to my questions.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
6. There are people who will fill in for me if I am unable to do something.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
7. I am able to work (including work in home).	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
8. My work (including work in home) is fulfilling.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
9. I am able to enjoy life "in the moment".	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
10. I am sleeping well.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
11. I am enjoying my usual leisure pursuits.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
12. I feel sad.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
13. I feel like my life is a failure.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
14. I feel nervous.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
15. I am worried about dying.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
16. I feel like everything is an effort.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
17. I am worried that my illness will get worse.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4

Below is a list of statements concerning how you're dealing with breast cancer. Please indicate how much you agree/disagree with each statement. [CHECK ONE BOX PER LINE]

In the past 7 days ...

		Disagree very much	Disagree	Neither agree nor disagree	Agree	Agree very much
1.	I needed more information about breast cancer from the perspective of patients who have been there.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
2.	I needed more understandable information about breast cancer.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
3.	I needed more information about the latest breast cancer research.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
4.	I needed more contact with people who understood what I was going through.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
5.	I needed help making decisions.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
6.	I understood what my doctor told me.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
7.	I was confident that I could have a positive effect on my health.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
8.	I set some definite goals to improve my health.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
9.	I actively worked to improve my health.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4

For each of the following questions, please check the box for the answer that comes closest to the way you have been feeling during the past month. [CHECK ONE BOX PER LINE]

"Because of breast cancer, during the past month I felt ..."

	Never	Rarely	Sometimes	Often	Always
1. Helpless	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
2. Tense	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
3. Loved/Cared for	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
4. Angry	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
5. Hopeless	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
6. Worried	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
7. Supported	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
8. Frustrated	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
9. Sad	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
10. Anxious	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Please indicate how true each statement is for you. [CHECK ONE BOX PER LINE]

During the past 7 days...

	Does not apply	Not at all	A little bit	Some- what	Quite a bit	Very much
1. I was short of breath.		☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
2. I was self-conscious about the way I dress.		☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
3. I was bothered by swollen or tender arms.		☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
4. I felt sexually attractive.		☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
5. I worried about the risk of cancer in other family members.	☐	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
6. I worried about the effect of stress on my illness.		☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
7. My change in weight bothered me.	☐	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
8. My hair loss bothered me.	☐	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
9. I was able to feel like a woman.		☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
10. My skin bothered me as a result of radiation treatments.	☐	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
11. I was fatigued.		☐ 0	☐ 1	☐ 2	☐ 3	☐ 4

For the question below, please check the box which best describes how you have been feeling in the last week.
In general, would you say you have been: [CHECK ONLY ONE BOX]

- ☐1 Feeling normal with no complaints and able to carry on your usual activities
- ☐2 Performing normal activities with some effort and minor signs of illness
- ☐3 Unable to carry on your usual activities or do physical tasks. Requiring occasional assistance but in bed less than 50% of the daytime
- ☐4 Disabled, requiring special care and assistance in most activities and in bed more than 50% of the daytime, but not all day
- ☐5 Very sick, hospitalized for some time or in bed all of the time

Please check how much you agree or disagree with the following statements [CHECK ONE BOX PER LINE]

	Disagree very much	Disagree	Neither Agree nor Disagree	Agree	Agree very much
During the past 7 days...					
1. It was difficult for me to find effective solutions for health problems that come my way.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
2. I handled myself well with respect to my health.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
3. I succeeded in the projects I undertook to improve my health.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
4. I was generally able to accomplish my goals with respect to my health.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
5. I found the efforts to change things I didn't like about my health were ineffective.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
6. I was able to do things for my health as well as most other people.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
In general...					
7. My plans for my health don't work out well.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
8. No matter how hard I try, my health doesn't turn out the way I would like.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4

On one of the first surveys you filled out, you indicated that you had made the following treatment decision:

We would like to know how you feel about that decision now. Please indicate how much you agree/disagree with the following statements in regards to the above decision. [CHECK ONE BOX PER LINE]

	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
1. My treatment choice was sound.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
2. I am satisfied with my treatment choice I made.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
3. My treatment choice was the right one for my situation.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
4. I am satisfied that my treatment choice was consistent with my personal values.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
5. I feel I made an informed choice.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
6. Knowing what I know now, I would still make the same decision today.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

The items below deal with ways you have been coping with the stress in your life since you found out you have breast cancer. Different people deal with stress in different ways. We are interested in how you have tried to deal with stress. Don't answer on the basis of whether or not it seems to be working or not – just whether or not you're doing it. [CHECK ONE BOX PER LINE]

In the past 2 weeks ...	I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
1. I've been turning to work or other activities to take my mind off things.	☐ ₁	☐ ₂	☐ ₃	☐ ₄
2. I've been trying see breast cancer in a different light, to make it seem more positive.	☐ ₁	☐ ₂	☐ ₃	☐ ₄
3. I've been criticizing myself.	☐ ₁	☐ ₂	☐ ₃	☐ ₄
4. I've been looking for something good in what is happening.	☐ ₁	☐ ₂	☐ ₃	☐ ₄
5. I've been making jokes about breast cancer.	☐ ₁	☐ ₂	☐ ₃	☐ ₄
6. I've been doing something to think about breast cancer less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.	☐ ₁	☐ ₂	☐ ₃	☐ ₄
7. I've been trying to find comfort in my religion or spiritual beliefs.	☐ ₁	☐ ₂	☐ ₃	☐ ₄
8. I've been blaming myself for things that happened.	☐ ₁	☐ ₂	☐ ₃	☐ ₄
9. I've been praying or meditating.	☐ ₁	☐ ₂	☐ ₃	☐ ₄
10. I've been making fun of the situation.	☐ ₁	☐ ₂	☐ ₃	☐ ₄
11. I have been helping other women with breast cancer.	☐ ₁	☐ ₂	☐ ₃	☐ ₄

HEALTH CARE USE AND SATISFACTION

Use the table below to describe your ***in-person visits over the last two months*** to various health care providers. In each row is a different kind of health care provider, and the columns are number of visits, length of visits, and overall satisfaction. If you haven't used a certain kind of health care provider in the last two months, leave the whole row blank. We've filled in a sample in the first row to show you how someone might answer. Do not include the time you may have spent overnight in the hospital or for day surgeries in this table. Hospitalizations and surgeries will be covered on the following page.

IN-PERSON VISITS TO HEALTH CARE PROVIDERS

	Number of times your visited in the last 2 months	Average amount of time you spent with providers (specify minutes or hours)*	Overall, how satisfied were you with visits to this provider? (Use a 1 to 5 scale, 1=very dissatisfied to 5=very satisfied)
Example	2 visits	30 minutes	4
Primary Doctor (e.g. Internist) - NOT Breast Cancer Specialist			
Surgeon			
Plastic Surgeon			
Radiologist			
Oncologist			
Mental Health Provider (e.g. psychologist, counselor, therapist)			
Other Specialty Clinic (dermatologist, etc.)			
Outpatient Lab Visit (e.g. blood test, x-ray, mammogram, etc.)			
Emergency Room			
Non-Medical Doctor Office (e.g. osteopath, chiropractor)			
Dental Clinic (dentist, oral surgeon, etc.)			
Alternative Care Provider (e.g. massage, acupuncture, etc.)			
Telephone consultations			

*Include time spent with all provider staff (doctors, nurses, pharmacists, etc.)

Use the table below to describe your **hospital visits (either overnight stays or day surgeries)** over the last two months. In the first column is the type of care (day surgery, overnight hospital stays). The next column asks for reason for stay (such as mastectomy, etc). Then fill in length of stays (# hours or days), and finally your overall satisfaction with the care you received. If you have not had any day surgeries or overnight hospital stays in the last 2 months skip to question #1 on this same page.

OVERNIGHT HOSPITAL VISITS AND DAY SURGERIES

DURING THE LAST 2 MONTHS...	Reasons for day surgery or overnight hospitalization (e.g. lumpectomy, mastectomy...)	Number of hours (if day surgery), or number of days (if overnight stays)	Overall, how satisfied were you with your care? (Use a 1 to 5 scale, 1=very dissatisfied to 5=very satisfied)
Day Surgery (not overnight stays)			
Overnight Hospital Stays			

Think about **all your health care during the past two months** (doctors, dentists, hospitals, therapists, emergency rooms). Mark whether you agree or disagree with the following statements. [CHECK ONE BOX PER LINE]

In the past 2 months...	Disagree very much	Disagree	Neither Agree nor Disagree	Agree	Agree very much
1. I thought about what was going to happen ahead of time.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
2. I felt comfortable with how actively I participated in my care.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4

Please answer the following questions:

- Today's date: _____
- What type of health insurance coverage do you have (include coverage obtained through a spouse or relative)? [CHECK ALL THAT APPLY]
 - ☐ 1 Private group insurance (through you/spouse's employer, union or trade group)
 - ☐ 2 Individual policy
 - ☐ 3 Medicaid (also called Title 19 or Medical Assistance)
 - ☐ 4 Medicare, Part A (pays for hospital bills)
 - ☐ 5 Medicare, Part B (pays for doctor's bills)
 - ☐ 6 Medigap policy (supplementary private insurance to Medicare)
 - ☐ 7 CHAMPUS or CHAMPVA
 - ☐ 8 Other: _____
 - ☐ 9 No insurance

3. *With whom do you currently live?* [CHECK ALL THAT APPLY].

- ☐₁ I live by myself
☐₂ I live with my partner (husband, lover)
☐₃ I live with one or more dependent children,
Please list ages and sex of dependent children _____
☐₄ I live with one or both of my parents
☐₅ I live with other family members
☐₆ I live with a friend or friends
☐₇ Other, please specify _____

4. *Has your breast cancer spread (metastasized) to other parts of your body other than your lymph nodes?*

- ☐₀ No
☐₁ Yes, when did you learn this (give approximate date): _____

5. *Have you had a recurrence of your breast cancer?*

- ☐₀ No
☐₁ Yes, when did you learn this (give approximate date): _____

6. *What is the stage of your cancer?* [CHECK ONE BOX]

- ☐₀ Stage 0
☐₁ Stage 1
☐₂ Stage 2
☐₃ Stage 3
☐₄ Stage 4
☐₅ Inflammatory
☐₆ Other _____
☐₇ Don't Know

7. *Write in the actual or scheduled dates for surgeries that you have completed, and those that you have scheduled. Also mark any other surgeries you are considering.*

	Start Date (give approximate dates):	Considering
• Radical mastectomy	_____	☐
• Modified radical mastectomy	_____	☐
• Lumpectomy	_____	☐
• Breast reconstruction	_____	☐
• Oophorectomy (ovary removal)	_____	☐
• Prophylactic (preventive) mastectomy of unaffected breast:	_____	☐
• Other _____	_____	☐

8. For each of the following breast cancer treatments, give the approximate starting and ending dates, or mark the box if you are seriously considering it. Give dates if you have done it, are doing it, or are planning a treatment.

	Start Date (give approximate dates):	End Date	Considering
• Chemotherapy	_____	_____	☐
• Radiation	_____	_____	☐
• Hormone Therapy (Tamoxifen, Halotestin)	_____	_____	☐
• High Dose Chemo or Bone Marrow Transplant	_____	_____	☐
• Other _____	_____	_____	☐

9. In addition to your prescribed treatments, what else are you doing for your breast cancer (diet, homeopathy, acupuncture, therapeutic touch, etc.)? Please list below:

In the last two months how **EASY WAS IT FOR YOU TO GET** information about breast cancer from the following: [CHECK ONE BOX PER LINE]

	VERY DIFFICULT	DIFFICULT	NEITHER EASY NOR DIFFICULT	EASY	VERY EASY
10A Books or articles	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
10B Audio or video tapes	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
10C Doctors or nurses	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
10D Other Patients	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
10E Family or friends	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
10F The Internet	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
10G CHESS	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

In the last two months **HOW MUCH DID YOU USE** the following resources to get information about breast cancer? [CHECK ONE BOX PER LINE]

	NOT AT ALL	ONCE OR TWICE	ATLEAST ONCE A MONTH	WEEKLY	ALMOST EVERY DAY	EVERY DAY
11A Books or articles	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
11B Audio or video tapes	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
11C Doctors or nurses	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
11D Other Patients	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
11E Family or friends	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
11F The Internet	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
11G CHESS	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

HOW USEFUL were each of the following in regards to information about breast cancer?
[CHECK ONE BOX PER LINE]

	NOT AT ALL	VERY LITTLE	LITTLE	SOME	A LOT	A GREAT DEAL
12A Books or articles	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
12B Audio or video tapes	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
12C Doctors or nurses	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
12D Other Patients	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
12E Family or friends	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
12F The Internet	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
12G CHESS	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

In the last two months **HOW USEFUL** were each of the following in terms of **MAKING A DECISION** in regards to breast cancer? [CHECK ONE BOX PER LINE]

	NOT AT ALL	VERY LITTLE	LITTLE	SOME	A LOT	A GREAT DEAL
13A Books or articles	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
13B Audio or video tapes	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
13C Doctors or nurses	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
13D Other Patients	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
13E Family or friends	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
13F The Internet	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
13G CHESS	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Please rate how **USEFUL** each of the following resources was in getting **EMOTIONAL SUPPORT**.

[CHECK ONE BOX PER LINE]

	NOT AT ALL	VERY LITTLE	LITTLE	SOME	A LOT	A GREAT DEAL
14A Books or articles	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
14B Audio or video tapes	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
14C Doctors or nurses	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
14D Other Patients	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
14E Family or friends	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
14F The Internet	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
14G CHESS	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

In the last two months **HOW MUCH HAVE YOU USED** the following resources to help you get **EMOTIONAL SUPPORT**? [CHECK ONE BOX PER LINE]

	NOT AT ALL	ONCE OR TWICE	AT LEAST ONCE A MONTH	WEEKLY	ALMOST EVERY DAY	EVERY DAY
15A Books or articles	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
15B Audio or video tapes	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
15C Doctors or nurses	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
15D Other Patients	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
15E Family or friends	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
15F The Internet	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
15G CHESS	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

We have included a picture of the CHESSE Services Menu in order to refresh your memory about the various services in CHESSE. Please indicate how helpful each of the following CHESSE services are to you.

Overall, how useful are each of the following CHESSE services? [CHECK ONE BOX PER LINE]

Not at all A little bit Some-what Quite a bit Very much

1 Overview of Breast Cancer ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

Decision and Planning Guide

2 Decisions Notebook (within Decisions, Decisions) ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

3 Learning from others (within Decisions, Decisions) ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

4 Action Plan ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

5 Consumer Guide ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

6 Resource Directory ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

Personal Space

7 Health Tracking ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

8 Assessments ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

9 Journaling ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

What's New

10 CHESSE News ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

11

Reading Room

12 Questions and Answers ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

13 Instant Library ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

Other Sites

14 Web Links ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

15 Medline ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

16 Evaluating Web Info ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

Connecting with Others

17 Personal Stories ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

18 Discussion Group ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

19 Ask an Expert ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

20 Video Gallery ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

Beginner's Guide

21 Basic Web Skills ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

22 Getting Started ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

23 About CHESSE ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

1. How much does UNDERSTANDING YOUR SITUATION affect your ability to cope with breast cancer?
 Not at all ☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10 Very much so

2 Overall, how much has CHESS helped you to cope with breast cancer?
 Not at all ☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10 Very much so

3 Overall, how much has CHESS helped you in your decision making in regards to breast cancer?
 Not at all ☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10 Very much so

*How much do you like each of the following characteristics of **CHESS**? [CHECK ONE BOX PER LINE]*

	Not at all	A little bit	Some- what	Quite a bit	Very much
1 I can get information	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
2 I can analyze situations	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
3 I can communicate with others	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
4 The information is up to date	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
5 The information is trustworthy	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
6 I can find information easily	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
7 I got frustrated by how long it took for the information to appear on the screen (download time)	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4

*How much do you like each of the following characteristics of the **Internet**? [CHECK ONE BOX PER LINE]*

	Not at all	A little bit	Some- what	Quite a bit	Very much
1 I can get information	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
2 I can analyze situations	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
3 I can communicate with others	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
4 The information is up to date	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
5 The information is trustworthy	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
6 I can find information easily	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
7 I got frustrated by how long it took for the information to appear on the screen (download time)	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4

1 What do you like MOST about CHESS?

2 What do you like LEAST about CHESS?

3 How has CHESS helped you deal with your breast cancer?

4 What were the things that interfered with or prevented you from using CHESS more?

This image shows a single sheet of white paper with horizontal blue or grey ruling lines. The lines are evenly spaced and run across the width of the page. There is no handwriting or other markings on the paper.

Suzy's Story

In the space below, please write what you think about this story. You do not need to summarize it.

Use the following scales to tell us what you think about the research described in the story.
[CHECK ONE BOX PER LINE]

Is it...	Not at all	A little	Some	Pretty much	Very
1. Trustworthy	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
2. Careful	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
3. Complete	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
4. Biased/slanted	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
5. Clear	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
6. Important	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
7. Surprising	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

How much did you think about the following things when you read the story: [CHECK ONE BOX PER LINE].

	Not at all	A little	Some	Pretty much	Very
1. What kind of website the story is on.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
2. Who paid for the survey.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
3. Who actually did the survey.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
4. Whether the researchers were really scientists.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
5. Whether the survey had been published.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
6. Whether the results of the study fit with earlier findings.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
7. How many people the scientists studied.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
8. Who the scientists studied.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
9. Whether the reporter's ideas about the results were right.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Think about your use of the world wide web for health or science information. How much do you agree or disagree with the following statements. [CHECK ONE BOX PER LINE].
(If you have not used the Web for health or science information, you are finished – Thank you!)

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
1. I think about whether an expert on a website is an expert.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
2. I think about whether to trust the information on a website.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
3. I think about how to tell if the website is really a commercial for a product.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
4. I think about who pays for the website when I look at it.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
5. I think about whether the research study can really support what a reporter is saying about it.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
6. I think about what a breast cancer study's results mean.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
7. I think about whether a study's results can be trusted.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
8. I think about whether a journalist who is describing the study really understands it.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
9. I think about whether I should believe a study if the results are new or surprising.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
10. I think about what I've heard before on an issue before I believe the results of a new study.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
11. I'm skeptical when I hear claims about breast cancer that contradict what I've heard before.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
12. I think about whether the people studied in breast cancer research are enough like me.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
13. I discount research that doesn't rely on a scientifically selected sample of people.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
14. I think about whether the research conclusions are based on a few personal experiences.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
15. When I read about cancer risks, I think about whether I am at risk and how much.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
16. I think about what I need to do to reduce my risk of getting cancer.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
17. I know how to understand most information graphics.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
18. I am comfortable when data are presented in percents..	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Thank you for completing this survey. Please send it back in the self addressed stamped envelope provided. If you have any questions call 1-800-361-5481. Thanks again!

Appendix # 7

CHES Project:

Comprehensive Health Enhancement Support System

**9-Month Post Test
CHES**

If you have any questions please contact:

*Fiona McTavish
University of Wisconsin – Madison
Center for Health Systems Research and Analysis
1124 WARF Building
610 Walnut Street
Madison, WI 53705*

1-800-361-5481 or 1-608-262-7852

Fmctavish@chsra.wisc.edu

Code # _____

Please indicate how much you agree or disagree with each of the following statements checking the appropriate box to the right of each statement.

Coping with Breast Cancer

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
Information Needs:					
1 I can ask any question to people who have been through similar experiences.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
2 I can get answers to my questions at any time.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
3 I can easily get the information I need.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
4 I have access to practical experts.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
Emotional Support:					
5 Whenever I worry, there is someone I can go to.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
6 I am building a bond with other women with breast cancer.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
7 I feel stronger knowing there are others in my situation.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
9 I've been getting emotional support from others.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
10 I can get support from people who understand.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
11 It helps me to be able to share my feelings and fears.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
Instrumental Needs:					
12 I get practical, concrete advice on how to go through my treatment.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
13 There is no one I can turn to for help when I need it.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
14 Someone steps in if there are everyday things I can't do because of my illness.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
15 I feel comfortable discussing my cancer with others.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Please indicate how much you agree or disagree with each of the following statements checking the appropriate box to the right of each statement.

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
Relationship with Health Care Providers:					
16 I am comfortable discussing my treatment options with my doctor.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
17 I know what questions to ask my health care provider.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
18 I am able to be assertive with my health care providers.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
19 I can manage my own care and be sure that the right treatment is given.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
20 I trust my doctor.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
Relationship with My Family:					
21 The help I have received has reduced the burden on my family.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
22 I have had enough information to help my daughter(s).	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
23 My family does not support me.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
Strength:					
24 I have the help I need to go on with my life.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
25 I feel as though I have the strength to deal with my breast cancer.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
Emotions:					
26 The information and support I have received have helped reduce my fear of cancer.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
27 I am not afraid to walk away from treatment if it seems right to me.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
28 I am able to understand statistics about breast cancer treatment.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
29 The information and support I have received have made me less anxious.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

The items below deal with ways you have been coping with the stress in your life since you found out you have breast cancer. Obviously different people deal with things in different ways, but I am interested in how you have tried to deal with it. I want to know to what extent you've been doing what the item says. How much or how frequently. Don't answer on the basis of whether or not it seems to be working or not – just whether or you're doing it. Try to rate each item separately in your mind from the others. Make your answers as true for YOU as you can.

In the past 2 weeks ...	I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
1. I've been turning to work or other activities to take my mind off things.	☐ 1	☐ 2	☐ 3	☐ 4
2. I've been trying see it in a different light, to make it seem more positive	☐ 1	☐ 2	☐ 3	☐ 4
3. I've been criticizing myself	☐ 1	☐ 2	☐ 3	☐ 4
4. I've been looking for something good in what is happening	☐ 1	☐ 2	☐ 3	☐ 4
5. I've been making jokes about it	☐ 1	☐ 2	☐ 3	☐ 4
6. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping	☐ 1	☐ 2	☐ 3	☐ 4
7. I've been trying to find comfort in my religion or spiritual beliefs	☐ 1	☐ 2	☐ 3	☐ 4
8. I've been blaming myself for things that happened	☐ 1	☐ 2	☐ 3	☐ 4
9. I've been praying or meditating	☐ 1	☐ 2	☐ 3	☐ 4
10. I've been making fun of the situation	☐ 1	☐ 2	☐ 3	☐ 4
11. I have been helping other women newly diagnosed with breast cancer	☐ 1	☐ 2	☐ 3	☐ 4
12. I have been inspired by other women who have had breast cancer	☐ 1	☐ 2	☐ 3	☐ 4

Knowledge and Understanding

Please indicate how much you agree or disagree with each of the following statements checking the appropriate box to the right of each statement.

<i>At this point, I feel I understand...</i>	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
1. How far advanced my cancer is and how far it has spread	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
2. What the likelihood of being a long term survivor is	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
3. How treatment will affect my ability to carry on my usual social activities	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
4. How my family and close friends will be affected by my cancer	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
5. How to care for myself at home	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
6. How treatment will affect my feelings about my body and my sexuality	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
7. The risks and benefits of different treatments	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
8. Whether my children or other members of my family are at risk of getting breast cancer	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
9. The treatment choice(s) I have	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
10. How to handle the side effects of treatments	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
11. How to deal with and get through treatment	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
12. What the side effects of treatment will feel like	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
13. How to reduce my stress	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
14. How to deal with financial pressures associated with my cancer	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
15. How cancer will affect the quality of my life	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
16. How to communicate with my doctors	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Below is a list of statements that other people with breast cancer have said are important. By checking one box per line, please indicate how true each statement has been for you during the past 7 days.

EMOTIONAL WELL-BEING

	Not at all	A little bit	Some- what	Quite a bit	Very much
1. I feel sad	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
2. I am losing hope in the fight against my illness	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
3. I feel nervous	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
4. I am worried about dying	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
5. I am worried that my condition will get worse	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄

FUNCTIONAL WELL-BEING

	Not at all	A little bit	Some- what	Quite a bit	Very much
6. I am able to work (including work in home)	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
7. My work (including work in home) is fulfilling	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
8. I am able to enjoy life "in the moment"	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
9. I am sleeping well	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
10. I am enjoying my usual leisure pursuits	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
11. I am content with the quality of my life	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄

SOCIAL SUPPORT

	Not at all	A little bit	Some- what	Quite a bit	Very much
12. There are people I could count on for emotional support	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
13. There are people I could rely on when I needed help doing something	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
14. I feel like no one cared about me	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
15. I am pretty much all alone	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
16. There is no one I could turn to for help when I needed it	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
17. There is no one who can help me find out the answers to my questions	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
18. There are people who will help me evaluate things I'm finding out about my illness	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄

For the question below, please check the box which best describes how you have been feeling in the last week.
In general, would you say you have been:

- ☐₁ Feeling normal with no complaints and able to carry on your usual activities
- ☐₂ Performing normal activities with some effort and minor signs of illness
- ☐₃ Unable to carry on your usual activities or do physical tasks. Requiring occasional assistance but in bed less than 50% of the daytime
- ☐₄ Disabled, requiring special care and assistance in most activities and in bed more than 50% of the daytime, but not all day
- ☐₅ Very sick, hospitalized for some time or in bed all of the time

Below is a list of statements concerning the amount of information about breast cancer you feel you need. By checking one box per line, please indicate how true each statement has been for you during the past 7 days. [CHECK ONE BOX ON EACH LINE]

- | | Strongly
Disagree | Disagree | Neither
Agree
nor
Disagree | Agree | Strongly
Agree |
|--|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|
| 1. I need more information about breast cancer | ☐ ₁ | ☐ ₂ | ☐ ₃ | ☐ ₄ | ☐ ₅ |
| 2. I need more social support | ☐ ₁ | ☐ ₂ | ☐ ₃ | ☐ ₄ | ☐ ₅ |
| 3. I need more help making decisions | ☐ ₁ | ☐ ₂ | ☐ ₃ | ☐ ₄ | ☐ ₅ |
| 4. I have sources of information I can turn to | ☐ ₁ | ☐ ₂ | ☐ ₃ | ☐ ₄ | ☐ ₅ |
| 5. I understood what my doctor asked me to do | ☐ ₁ | ☐ ₂ | ☐ ₃ | ☐ ₄ | ☐ ₅ |

ADDITIONAL CONCERNS BECAUSE OF MY BREAST CANCER

During the past 7 days:

	Not at all	A little bit	Some- what	Quite a bit	Very much	Does not apply
35 I was short of breath	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	
36 I was self-conscious about the way I dress	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	
37 I was bothered by swollen or tender arms	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	
38 I felt sexually attractive	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	
39 My hair loss bothered me	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅
40 I worried about the risk of cancer in other family members	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅
41 I worried about the effect of stress on my illness	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	
42 My change in weight bothered me	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅
43 I am able to feel like a woman	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	

BREAST CANCER HISTORY

1 When was your breast cancer first diagnosed (give approximate date): _____

2 Has your breast cancer spread (metastasized) to other parts of your body other than your lymph nodes?

☐₀ No

☐₁ Yes, when did you learn this (give approximate date): _____

3 Have you had a recurrence of your breast cancer?

☐₀ No

☐₁ Yes, when did you learn this (give approximate date): _____

4 Write in the actual or scheduled dates for surgeries that you have completed, and those that you have scheduled. Then mark any other surgeries you are considering.

	Date (give approximate date):	Considering
Radical mastectomy	_____	☐
Modified radical mastectomy	_____	☐
Lumpectomy	_____	☐
Breast reconstruction	_____	☐
Oophorectomy (ovary removal)	_____	☐
Prophylactic (preventive) mastectomy of unaffected breast	_____	☐
Other	_____	☐

- 5 For each of the following breast cancer treatments, give the approximate starting and ending dates, or mark the box if you are seriously considering it. Give dates if you have done it, are doing it, or are planning a treatment.

	Start Date	End Date	Considering
Chemotherapy	_____	_____	☐
Radiation	_____	_____	☐
Hormone therapy (e.g., Tamoxifen, Halotestin)	_____	_____	☐
High-dose chemotherapy & bone marrow transplant	_____	_____	☐
Other: _____	_____	_____	☐

- 6 In addition to your prescribed treatments, what else are you doing for your breast cancer (diet, homeopathy, acupuncture therapeutic touch, etc.)? Please list below:

BACKGROUND & LIFESTYLE

- 1 Today's date: _____
- 2 What type of health insurance coverage do you have (include coverage obtained through a spouse or relative)?
- ☐₁ Private group insurance (through you/spouse's employer, union or trade group)
 - ☐₂ Individual policy
 - ☐₃ Medicaid (also called Title 19 or Medical Assistance)
 - ☐₄ Medicare, Part A (pays for hospital bills)
 - ☐₅ Medicare, Part B (pays for doctor's bills)
 - ☐₆ Medigap policy (supplementary private insurance to Medicare)
 - ☐₇ CHAMPUS or CHAMPVA
 - ☐₈ Other: _____
 - ☐₉ No insurance
- 3 With whom do you currently live [CHECK ALL THAT APPLY]?
- ☐₁ I live by myself
 - ☐₂ I live with my partner (husband, lover)
 - ☐₃ I live with one or more dependent children ,
Please list ages and sex of dependent children _____
 - ☐₄ I live with one or both of my parents
 - ☐₅ I live with other family members
 - ☐₆ I live with a friend or friends
 - ☐₇ Other, please specify _____

REACTIONS TO CHESS

Please indicate how helpful each of the following CHESS services are to you by checking one box on each line.

<i>How helpful are each of the following CHESS services in providing you with SOCIAL SUPPORT?</i>		Not at all	A little bit	Some-what	Quite a bit	Very much
1	Questions and Answers	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
2	Instant Library	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
3	Getting Help/Support	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
4	Personal Stories	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
5	Ask an Expert	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
6	Discussion Group	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
7	Decisions and Conflicts	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
8	Action Plan	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
9	Assessment	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
10	How much does SOCIAL SUPPORT affect your ability to cope with breast cancer?					
	Not at all	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
		☐ ₅	☐ ₆	☐ ₇	☐ ₈	☐ ₉
		☐ ₁₀	Very much so			

<i>How helpful are each of the following CHESS services for MAKING DECISIONS?</i>		Not at all	A little bit	Some-what	Quite a bit	Very much
11	Questions and Answers	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
12	Instant Library	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
13	Getting Help/Support	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
14	Personal Stories	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
15	Ask an Expert	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
16	Discussion Group	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
17	Decisions and Conflicts	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
18	Action Plan	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
19	Assessment	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
20	How much does MAKING DECISIONS affect your ability to cope with breast cancer?					
	Not at all	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
		☐ ₅	☐ ₆	☐ ₇	☐ ₈	☐ ₉
		☐ ₁₀	Very much so			

How helpful are each of the following CHESS services for UNDERSTANDING YOUR SITUATION?

	Not at all	A little bit	Some-what	Quite a bit	Very much
21 Questions and Answers	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
22 Instant Library	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
23 Getting Help/Support	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
24 Personal Stories	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
25 Ask an Expert	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
26 Discussion Group	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
27 Decisions and Conflicts	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
28 Action Plan	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
29 Assessment	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄

30 How much does UNDERSTANDING YOUR SITUATION affect your ability to cope with breast cancer?
 Not at all ☐₀ ☐₁ ☐₂ ☐₃ ☐₄ ☐₅ ☐₆ ☐₇ ☐₈ ☐₉ ☐₁₀ Very much so

31 Overall, how much has CHESS helped you to cope with breast cancer?
 Not at all ☐₀ ☐₁ ☐₂ ☐₃ ☐₄ ☐₅ ☐₆ ☐₇ ☐₈ ☐₉ ☐₁₀ Very much so

32 Overall, how much has CHESS contributed to your quality of life?
 Not at all ☐₀ ☐₁ ☐₂ ☐₃ ☐₄ ☐₅ ☐₆ ☐₇ ☐₈ ☐₉ ☐₁₀ Very much so

How much do you like each of the following characteristics of CHESS?

	Not at all	A little bit	Some-what	Quite a bit	Very much
33 I can get information	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
34 I can analyze situations	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
35 I can communicate with others	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄

36 What do you like MOST about CHESS?

37 What do you like LEAST about CHESS?

38 What have you learned from using CHESS?

39 How has CHESS changed your use of health care services?

40 What difference has CHESS made?

41 What else should CHESS have in it?

42 What else would you like to tell us?

43 How much would you say you have used CHESS?

Not at all	A little bit	Some- what	Quite a bit	Very much
☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄

44 What were the things that interfered with or prevented you from using CHESS more?

45 What would have made CHESS more useful or appealing?
