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#### **FOREWORD**

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## **Table of Contents:**

Front Cover	1
Standard Form (SF) 298	2
Foreword	3
Table of Contents	4
Introduction	5
Body	6
Conclusions	18
References	19
Appendices	21

#### INTRODUCTION

This project involves a prospective study of women who are at high risk for early onset breast cancer and their families in a time period spanning from prior to the offering of predictive testing to a year following their decision whether to obtain such testing. Predictive testing is now possible for mutations of both the BRCA1 and BRCA2 genes. Mutations of BRCA1 convey an 85% lifetime risk of breast cancer, as well as an unknown increase in the risk for ovarian cancer. Mutations of BRCA1 are thought to explain 15-25% of all inherited breast cancer and up to 90% of families with both breast and ovarian cancer. Mutations of BRCA2 carry a risk of breast cancer of 85% for women by age 80 and a risk of 15-20% for ovarian cancer by age 70. Mutations of BRCA2 also confer a risk of breast cancer in men of 6% by age 70. Mutations of BRCA2 are thought to explain 15-25% of all inherited breast cancer. As with BRCA1, current risk estimates for BRCA2 may change since these figures were derived from a skewed population of large, highly cancer-affected families and therefore may be overestimates.

Testing is already being offered to our research sample of high-risk women who have been participating in genetic linkage and mutation studies, and it has now also become commercially available. As many as 1 in 200-400 American women are carriers of mutations of these genes, and larger numbers can be expected to face the dilemma of whether to seek testing. Mutations of these genes are the first for which widespread testing for risk of late onset disease is appropriate, and the availability of the test raises some daunting and largely unprecedented issues. Women with positive family histories of breast cancer have expressed considerable interest in obtaining predictive testing. Yet little is known about the extent to which women who indicate they will utilize testing actually follow through, the anticipated benefits and drawbacks of knowledge of risk status influencing their choice, or about the psychological and social costs to these women and their families of having access to such information. Positive findings carry the threat of psychological and psychiatric morbidity for the women and family members, the disruption of family relationships, and the impairment of the women's surveillance and adherence behavior, but the degree of vulnerability and factors which identify the individuals and families at greatest vulnerability have not yet been determined. Yet, negative findings or not obtaining information concerning risk status may also have detrimental effects on the women and their families.

In the absence of a large body of directly relevant prior research, we are faced with an urgent need for basic descriptive data concerning women at high-risk for early onset breast cancer and their families; their psychosocial assets and liabilities, their attitudes and beliefs, their intention to seek predictive testing, and their preparedness for possible results. This information is needed immediately for planning for the implications of testing being made available on a such large scale basis. Yet, we also have a historical opportunity to utilize these data in a prospective study of stress, coping, and decision making processes in these women and their families with the advantage of initial data having been obtained just prior to predictive testing for BRCA1 becoming an option for the individual women.

The project involves a longitudinal study of a sample of at least 300 high-risk women who are among the first being offered the option of testing for BRCA1 and their family members. They receive baseline in-depth assessment by questionnaire and telephone interview, and initial assessments had been started at the point of receipt of funding from the DoD. Funding from the DoD Breast Cancer Initiative was sought to complete initial assessments and to follow the women over time with 4 reassessments: when testing for BRCA1 becomes available to the individual women, after receipt of any results, and 3 and 9 months after testing. Husbands of the high risk women are being assessed by questionnaire and they will be reassessed along with siblings of the women at the time of

the offering of testing to the individual women and again at 3 and 9 months after following testing. Our sample is well described medically and in terms of family history. The women and their families are being assessed with a set of psychosocial measures which are carefully chosen for their likelihood of immediate relevance to planning and the design of clinical protocols, but also for their use in understanding of basic individual and family stress and coping processes. Variables assessed include attitudes and beliefs; personality traits; social support and family functioning; psychological distress and psychiatric morbidity; and decisions and behavior relevant to their management of risk for cancer. These measures will also allow estimation of psychosocial costs associated with the option of testing and modeling of the intention whether to obtain testing and subsequent decision-making and behavior. The resulting longitudinal data will have a direct application in estimating the need for services, refining appropriate clinical protocols, and suggesting requisite training for personnel providing services.

The first overall objective of this study is to assess psychological distress, current and past psychiatric disorder and impairment in women at high-risk for breast and ovarian cancer who are anticipating the prospect of genetic testing. Establishing base rates of distress and impairment permits us to evaluate the mental health needs of these women anticipating testing, and it also serves as a first step toward evaluating the incremental distress incurred by risk notification. That is, levels of distress and morbidity following disclosure need to be evaluated in terms of what these levels were prior to disclosure. Apparently high rates of distress and disorder following testing might nevertheless represent a reduction from preexisting levels. The second objective is to compare the two groups of women within our sample: One group who had been previously diagnosed with breast cancer, and one group who had not yet been affected. Initial differences between the two groups are important for the evaluation of the extent to which unaffected women subsequently become like affected women upon receipt of findings that they carry the altered gene. On the other hand, it might prove to be the case that heightened awareness of high risk status among unaffected women has already resulted in comparable levels of distress and disorder. A final objective is to evaluate the extent to which our self-report data are successful in identifying current and past psychiatric diagnoses. Self-report screening instruments are economical and readily administered, but tend to have the disadvantage of low specificity as a means of identifying psychiatric cases (Coyne, 1994). Furthermore, the prevalence of both distress and disorder in a given population may affect the performance of the cutpoint which has been established for screening measures. This, one study found that the high rates of elevated scores on a screening instrument, but low levels of depression among adolescents rendered the established cutpoint for the screening instrument useless in detecting depression (Roberts. Lewinsohn, & Seeley, 1991) The inclusion of both self-report measures and diagnoses based on semi-structured interview allows us to examine the performance of the self-report measures in terms of their possible use as the first stage of two-stage strategies for identifying psychiatric morbidity. Even if their specificity proved to be as modest as anticipated, low scores might still prove valuable in screening out women who would be unlikely to be found to have psychiatric morbidity in a diagnostic interview.

#### **BODY**

The project involves an in-depth assessment and tracking of four interrelated groups: (1) at least 300 proband women (presently 480) who have a risk for early onset breast cancer based on two or more affected relatives and who will be among the first persons to have access to predictive testing for BRCA1 mutation; (2) the spouses of the approximately 230 women who are married; (3) a stratified random sampling of 120 of the women's unaffected sisters (those who have not been diagnosed with breast cancer) and (4) 80

brothers. Key variables include the women and family members' stress and social support processes, including cancer-related stress and support; psychological distress and psychiatric morbidity; marital and family functioning; psychological characteristics presumed to affect the women's information-processing, decision-making, and subsequent adjustment; and the at-risk women's intentions to seek predictive testing and anticipated outcomes and plans for use of the information; relevant attitudes, beliefs, and expectations; and current surveillance and adherence behaviors. Assessment of the proband women is by self-report questionnaires and telephone interviews. Subsequent reassessments of the proband women's current cancer-related stress and support and beliefs, attitudes and intentions, distress, and psychiatric morbidity will also be by telephone interview and questionnaire. Assessments of husbands and siblings will be by self-report questionnaires within a month of receipt of funding. The at-risk women, spouses and siblings will then be reassessed as the option of predictive testing is made available to the individual women. A second reassessment will occur after testing has occurred and results are available, or when results would have been available had the proband woman not declined testing. A third reassessment will occur 4-8 weeks later after results are provided, and follow up assessments will occur at 6 and 12 months.

#### PROCEDURE AND ACCOMPLISHMENTS TO DATE

#### **Summary**

The first year was marked by the meeting of key objectives and successful confrontation with a variety of challenges and opportunities. Expansion of the Hereditary Breast and Ovarian Cancer Registry from which subjects are drawn allowed recruitment of a larger sample for baseline assessment. This was fortuitous because preliminary testing of blood samples from women already affected by breast and ovarian cancer in high risk families has now revealed that BRCA1 and BRCA2 account for less of the ostensibly hereditary breast cancer than previously predicted. At the present time, women from families that do not have an affected woman with a BRCA1 or BRCA2 mutation may not be offered testing. The implications of this are that many of the women in our sample will not progress to the stage of actually confronting the testing dilemma. Our substantially augmented sample allows us to nonetheless have a more than adequate size and statistical power for women who do progress to a choice about testing. The first year was also marked by delays in the offering of testing to individual women for a variety of technical and practical reasons spelled out below. We had anticipated this and had previously designed an interim assessment to be administered if one year passed after baseline assessment without a woman being offered testing. This interim assessment also served to reduce the burden of the baseline assessment by redistributing some of our trait measures to a second testing and it also involved the re-administration of measures of distress and other state variables likely to fluctuate over such a time period. As planned, women who progressed to having a choice about testing received these measures in their pre-counseling assessment. We also took advantage of a change in the of the Hereditary Breast and Ovarian Cancer Registry. Persons, both male and female, who have gotten results of genetic testing elsewhere are now being entered into the registry for the purposes of long term follow up. We have included them in our tracking sample. For some purposes they will be separated for data analysis, but for other purposes, they can be combined. This addition will very likely make our sample the largest data base concerning persons who have received genetic testing for risk of breast cancer.

Data cleaning, reduction, and entry are proceeding well. One of our objectives has been to produce as quickly as possible an assessment of baseline distress and psychiatric morbidity

among women anticipating genetic testing. This has been done, and the results are presented below. As we noted, these women are freer of problems than anticipated and we are now conducting analyses to understand this in terms of their social resources and family experience with cancer.

#### **Methods**

Women and their families participating in this study were drawn from the Hereditary Breast and Ovarian Cancer Registry originally started at the University of Michigan, but now housed at the University of Pennsylvania. To be included in the registry, unaffected women had to have at least two cases of either breast or ovarian cancer in their family, and affected women had to have at least one family member who had been affected. An alternative inclusion criterion was for women to have had ovarian cancer after prophylactic oophorectomy. A periodic informational letter to women enrolled in the registry made reference to the possibility of an impending longitudinal study of them and family members. To recruit subjects for the this psychosocial component of the University of Michigan/ University of Pennsylvania study, a cover letter, consent form, and questionnaire were sent to eligible enrollees in the registry. When the baseline questionnaire and consent form were returned, subjects were contacted by telephone in order to answer any questions and schedule the telephone interview. If we received neither a questionnaire or a mailback refusal form, we called subjects, explained the study, and offered to send another packet if necessary. At the point of actual receipt of funding, some of the women had already participated in the initial assessment and had been alerted to the possibility of their being asked to continue in a longitudinal study and to enlist family members. Women continuing to participate in the study will be again asked to solicit the involvement of spouses. Given the sensitive nature of risk information, concerns about confidentiality dictated that we utilize the women rather than contact the family members directly. We discussed the rationale with the women for their family members' involvement, underscored the voluntary nature of their choice whether to facilitate their family members' participation in the study, and if they so chose, provided them with strategies for contacting and enlisting them. Such preparation and training of the proband women had already been successfully used in obtaining initial and follow up biomedical and family history data from these families. When we were notified by women that family members had agreed to participate, we called them, explained the study, and sent a packet with a questionnaire and consent form.

The next scheduled assessment of the women is the Pre-Results and a number of the women and their siblings have either completed this assessment or recently received it.

Our ability to track these women and their families through the course of their being offered testing is dependent upon their actually being given this opportunity. A number of factors have affected the offering of testing in general and to specific individuals. Actual testing is now proceeding in our sample, but after considerable delay and only to certain individuals. Technology for genetic testing has been available for some time, but mutation analysis remains challenging. Both BRCA1 and BRCA2 are very large genes and mutations are scattered throughout the genes. Analyses of either of the entire genes would be labor intensive and expensive. Available laboratory techniques do not detect mutations on non-coded regions of the genes, but these may account for as many as 5-10% of mutations. Therefore, at the present time, the accuracy and informativeness of testing is hinged upon whether there is a known mutation of BRCA1 or BRCA2 identified in an individual in the family affected with either breast or ovarian cancer. If such a known mutation exists, than the detection of that mutation in another member of that family is highly accurate and informative. If no such mutation has been identified in a particular

family, then the only informative result for individual family members is when a mutation of BRCA1 or BRCA2 is identified. In the absence of mutation having been found in a family, a negative testing finding for a given individual is not informative. If a mutation is not identified for this individual, it does not mean that the cancer is not associated with a cancer susceptibility gene, only that no such mutation can be identified at this time. The net result of all of these considerations is not every individual is appropriate for testing. For the University of Pennsylvania Hereditary Breast and Ovarian Cancer Registry, the decision was made to analyze already collected blood samples from affected women. If an affected woman was found to have a mutation, testing was offered to her family. As in other hereditary breast cancer registries, it is being found that many ostensibly high risk families do not carry a known mutation of BRCA1 or BRCA2. This is stimulating a search for other genes associated with risk of breast cancer, but it also means that for now many women in the sample will not receive testing. Some have already been sent a letter explaining the predicament of their families with respect to testing. These women will continue to be studied. Essentially they had met criteria for inclusion in the registry, and based on this, they were led to believe that genetic testing would be an option. They are not being told that they are not members of a hereditary breast and ovarian cancer family, only that the families are not characterized by a known mutation of BRCA1 or BRCA2. This outcome is worthy of investigation and may have attendant psychological distress and other untoward consequences associated with it. Fortunately, we have baseline assessments of these women.

Women in the Hereditary Breast and Ovarian Cancer Registry are scattered across the country. In order to receive results, women who are not in close proximity to the University of Pennsylvania, University of Michigan, or other select sites must identify a physician and through that physician, provide a clinical consent. Only then will results be released. The shortage of such physicians and some difficulties in their understanding of the consent process has led to some delays, but release of test results is now proceeding. Concerted efforts are being made nationally to increase the availability of individuals qualified for counseling, disclosure of results, and follow up. We are coordinating our assessments with information from the University of Pennsylvania and collecting data as women proceed through the process of getting the opportunity to obtain test results.

#### **Measures**

Our selection of measures conforms to our original proposal. Copies of our batteries of instruments are included as an appendix. Table 1 lists the major measures.

#### Table 1: Initial Data Collection

#### **Proband Women**

Questionnaire	<u>Interview</u>	Interim Assessment
Demographics Health Locus of Control Risk Perception Intention to Seek Testing Knowledge, Beliefs and Attitudes Reasons for Seeking Testing Anticipated Reactions Cancer Worries Stressful Life Events Optimism (LOT) Miller Behavioral Styles Scale (MBSS) Hopkins-25, MOS-36, AUDIT Present and Future Self- Concept Dyadic Adjustment (DAS) General Family Functioning (FAD) Social Support & Cancer- Related Support Processes	Contextual Rating of Cancer Threat:    Affected Relatives    Relationship to         Proband    Outcome    Involvement of         Proband In Care    Effects on Proband's         Life SCID Depression, Anxiety, & Substance Use Modules Cancer-Specific Support Processes	HSCL-25, MOS-36 Cancer Worries FAD, Short-Form DAS Quality of Social Support Life Cycle Issues Receipt of Individual, Group, & Family, Counseling & Education COPE Relationship-Focused Coping CBCL Evaluation of Preventive Options
	Husbands Questionnaire	
Demographics Health Locus of Control Risk Perception Worries About Wife's Risk of Cancer Preference for Wife's Testing Relationship-Focused Coping	COPE Knowledge, Beliefs and Attitudes Anticipated Reactions Social Support & Cancer- Related Support Processes	Stressful Life Events CBCL LOT, MBSS, Hopkins-25, MOS-36 AUDIT DAS, FAD

#### **Sample**

Our sample currently consists of 480 women who have completed baseline assessments. OF these, 472 completed the telephone interviews. To date, 301 interim assessments have been collected. Data from husbands are collected at the point of the women's interim assessment, the first husband data are collected, and at this time, data have been collected from 177 husbands. Pre-Results data have been collected from 10 Probands and 4 siblings. In addition, follow up data have been collected from 15 men and women in the long term follow up subsample. Table 2 presents basic demographic data on the proband women. As can be seen, they are similar to other samples of persons seeking genetic services in that they are relatively well educated and high income.

<u>Table 2</u>

<u>Basic Demographic Data</u>

	ALL WOMEN	UNAFFECTED <u>WOMEN</u>	AFFECTED WOMEN
Age	52.7(12.2)	51.0(13.3)	54.2(11.0)
Religion Christian	77.7%	81.6%	74.1%
Marital Status Married/With Partner	83.1%	83.1%	82.9%
Number of Children	2.31(1.38)	2.26(1.51)	2.36(1.27)
Education At Least Some College	75.8%	71.4%	80%
Employed Outside Home	54.8%	55.8%	53.8%
Income	\$56,800	54,500	\$59,100

#### Study of Baseline Distress and Psychiatric Morbidity

As we noted, one of objectives for the first year was to finish collecting and to analyze baseline data concerning psychological distress and psychiatric morbidity. The Hopkins Symptom Checklist served as the measure of distress and a telephone interview using modules of the SCID served as the measure of current and lifetime psychiatric morbidity. These data were analyzed in conjunction with baseline concerning intention to get test results and cancer worries.

Psychological Distress. The 25 item version of the Hopkins Symptom Checklist (HSCL-25) was used to assess psychological distress. Heshbacher, Downing, and Stephansky (1978), found this version of the questionnaire reliable and highly correlated with the standard 58-item version (Derogatis et al., 1974). The HSCL-25 has a better balance of sensitivity and specificity than a number of other screening instruments such as the CES-D (Heshbacher et al. 1978; Hough et al. 1982). There is extensive data using this scale with healthy, physically ill, and psychiatric samples (Cohen, Coyne, & Duvall, 1993; Coyne & Smith, 1991; Coyne & Sonnega, 1995, Pepper & Coyne, 1996).

<u>Current Depression</u>, <u>Anxiety</u>, and <u>Alcohol Use Disorders and History of Depression</u>. Like other self-report screening instruments, our measures of psychological distress and alcohol

use have good sensitivity, but poorer specificity and they do not provide for diagnoses. A 2-stage screening in strategy is therefore appropriate (Dohrenwend & Shrout 1981; Newman, Shrout, Bland 1990). Women with elevated scores on measures of psychological distress and alcohol use and a subsample of those scoring below the cut points will be administered corresponding alcohol use and/or depression and anxiety and sections of the Structured Clinical Interview for DSM-IV (SCID-IP; First et al 1994).

The SCID utilizes trained mental health professionals and yields DSM-IV diagnoses. In addition to diagnoses, the SCID includes assessment of the severity of major depression according to DSM-IV criteria and assessment of past history of depression. The DIS utilizes lay interviewers, and one key difference between the two instruments is that the SCID utilizes the clinical judgment of the interviewer for decisions about explaining or rephrasing questions and accepting or probing respondents' answers. In contrast, the DIS is more like an interviewer-administered questionnaire with considerable constraint on what the interviewer can ask or infer (Coyne, 1994). Although the DIS has been used in the large scale ECA Study (Regier, Myers & Kramer 1984), there is some evidence of substantial discrepancy between the diagnoses made by lay interviewers using the DIS and standardized diagnoses made by psychiatrists (Anthony et al 1985). Moreover, discordance may be more frequent with nonpsychiatric populations when the depression being diagnosed is mild so that criteria are barely met by alternative rules, and this proves particularly important when correlates are examined rather than simple rates of detection (for a fuller comparison of the SCID-IP and DIS, see Coyne 1994). Discordance is similarly likely to arise when judgments must be made whether to consider heightened distress as an adjustment reaction, and such decisions are likely to be routine in assessing the proband women.

The SCID-IP is designed for use in a modular fashion so that an investigator can select, for a particular study, only those diagnostic modules that are relevant for a particular patient sample. For our purposes, the SCID-IP is modualized to assess history of depression and current mood disorders, alcohol use disorders, panic disorders, and generalized anxiety, and adjustment disorders. This decision is based on our own experience assessing psychiatric disorder in primary care, but also the NYSPI experience assessing homosexual men seeking testing for HIV antibody (Williams et al 1991). They initially included psychotic screening questions, the other anxiety disorders, and somatoform disorders but these areas of psychopathology were virtually never detected, so they dropped these sections to decrease interviewing time.

Questions can be raised about the conduct of diagnostic interviews by telephone. However, previous studies have shown the concordance of phone-administered diagnostic interviews with face-to-face interviews (Kendall et al 1992; Wells et al 1988; Potts et al 1990; Baer et al 1993), and as with other major research centers, we have been having satisfactory experiences with telephone interviewing.

<u>Cancer worries</u>. This measure was administered to the unaffected group only. The women were asked how often they worry about developing breast cancer and also the extent to which their worries interfered with their everyday lives. These measures had been validated in studies conducted by Caryn Lerman and her colleagues e.g. Lerman et al. 1994; Lerman & Croyle, in press; Struewing et al., in press).

Table 3 presents data concerning the intention to receive testing when it is offered. As can be seen, the majority of women express interest in obtaining results, but it remains to be seen the extent to which this expression of interest is reflected in the women actually choosing to receive their results when the opportunity is presented to them. This will undoubtedly prove to be an overestimate of the actual uptake of testing.

Table 3
Intention To Be Tested For Brca1 (%)

	ALL WOMEN	UNAFFECTED <u>WOMEN</u>	AFFECTED <u>WOMEN</u>
Definitely Will Immediately	64.2	55.2	75.0***
Definitely, Not Sure Immediately	10.2	15.5	4.2
Probably Will Immediately	9.4	9.7	9.2
Probably Will Not Immediately	4.1	9.0	4.2
Undecided	7.2	9.0	5.0
Probably Will Not	1.9	1.4	2.5
Definitely Will Not	0.4	0.7	0

\*\*\*p<.001

Table 4 (next page) provides data concerning the women's reasons for obtaining test results. While their motivation to reduce uncertainty was expected, it is noteworthy that the next strongest reason for the full sample is to find out about their children. This result is consistent with our anticipation of the salience of such family issues in the reasons for getting testing.

<u>Table 4</u>

<u>Reasons For Seeking Testing</u>

	ALL WOMEN	UNAFFECTED WOMEN	AFFECTED WOMEN
To Plan for Future	46.4	62.7	30.7***
To Reduce Uncertainty	64.6	79.4	48.2***
To Be More Careful About BSE	34.6	46.0	21.9
To Decide About Prophylactic Surgery	47.1	55.6	32.5***
To Decide About Family Planning	5.8	11.9	2.6
To Assess Risk To Children	61.7	51.6	72.8**
Family Urges Testing	17.4 *p<.05	15.1 **p<.01	13.2 ***p<.001

Table 5 provides data concerning these women's perceived risk of breast cancer. These women's estimates of their risk is not inconsistent with being a female member of a high risk family.

<u>Table 5</u>
Perceived Likelihood Of Breast Cancer

	ALL WOMEN	UNAFFECTED <u>WOMEN</u>	AFFECTED <u>WOMEN</u>
In the Near Future	35.2%	44.7%***	22.3%
In Lifetime	47.8%	60.3%***	31.9%

Table 6 presents the results obtained with the Hopkins Symptom Checklist. Interpretation of these results is assisted by making a comparison with our HSL-25 data obtained with other samples, presented in Table 7. Our sample, both affected and unaffected, is remarkable free of distress. This disconfirms expectations that at risk women seeking testing are a highly distressed group.

<u>Table 6</u> <u>Psychological Distress</u>

	All Women	Unaffected <u>Women</u>	Affected Women
Hopkins 25	37.5 (9.2)	37.4 (9.2)	37.7 (9.2)
% Above Cutoff	21%	21%	22.8%

Table 7
Psychological Distress In Other Samples

Cohen, Coyne, Duvall (1993):	
Adoptive Nonclinical	
Mothers Biological Nonclinical	34.52 (7.09)
Mothers	36.25 (8.9)
Adoptive Clinical Mothers	42 64 (12 2)
Biological Clinical	43.64 (12.3)
Mothers	41.30 (12.1)
Coyne & Smith (1991)	
Wives of Post-MI Patients	41.8 (10.2) 32%
Coyne & Sonnega (1995)	
Wives of CHF Patients	47.1 (12.8) 49%
Female CHF Patients	46.6 (14.1) 62%
Pepper & Coyne (1996)	
Depressed Female	
Outpatients	65.0 (11.30)

Table 8 presents the results obtained in the assessment of psychiatric morbidity using the telephone-administered SCID modules. Consistent with the data concerning psychological distress, this is a remarkably intact group of women, given their high risk status. The lifetime rates of depression are well within normal limits, but their rates of current disorder are even lower than what is found in representative samples of community residing women. Thus, the anticipation by some that these women would have a high prevalence of depression and anxiety disorders was clearly not confirmed.

<u>Table 8</u>
Psychiatric Morbidity (%)

	ALL WOMEN	UNAFFECTED <u>WOMEN</u>	AFFECTED <u>WOMEN</u>
Current Major Depression	1.1	0.4	1.9
Lifetime Major Depression	18.4	15.8	21.5
Current Major Depression (GMC)	0 .2	0.5	0
Lifetime Major Depression (GMC)	2.1	1.2	3.2
General Anxiety Disorder	0.6	0.8	0.5
Mixed Anxiety/Depression	0.6	1.2	0

Finally, Table 9 presents the data derived from standard measures of breast cancer worries. Understandably, the women have a moderate degree of such worries, but what is noteworthy is that the follow up question concerning impairment indicates that such worries do not substantially interfere with their lives.

Table 9

Breast Cancer Worries Among Unaffected High Risk Women

How often do you worry about developing breast cancer (1= Not at All, 5= All the Time)?	2.87	
To what extent do any worries about breast cancer interfere with your life (1= Not at All, 5= All the Time)?	1.63	

#### **DISCUSSION**

The women in our sample were remarkably free of psychological distress and psychiatric morbidity. Despite their increased risk for breast and ovarian cancer as well as their repeated exposure to breast cancer either in themselves or their relatives, they compared well with women drawn from other samples. Our findings have a number of implications. Most importantly, it appears that when the women approach the process of counseling, education, and decision making about testing, they will not be impaired by their pre-existing psychological state. That is not to say that the actual experience of counseling, having to make a decision about testing, or the receipt of positive results will not engender distress. However, the assumption that these women will approach the process of genetic testing with distress and psychiatric morbidity was not substantiated by our findings. Rather, the results suggest that any substantial elevations of distress and psychiatric morbidity following the counseling process are best attributed to that process and not to the preexisting state of the women. It follows that efforts to manage psychological distress and the education and consent process should focus on acute needs, rather than be based on the assumption of chronic psychological problems.

The findings reported in this study have a number of implications that go beyond the question of determining the psychological state of women seeking predictive testing for risk of breast cancer. We have demonstrated that long-term survivors of cancer can be relatively free of psychological distress and psychiatric morbidity. Even though over half our sample were survivors of breast cancer and had a greater lifetime incidence of depression than the unaffected women, these women were well within the expected prevalence for a representative sample of community residing women. The low levels of distress and morbidity reported in this study suggest that previous findings of elevated distress may be confined to early adjustment to a diagnosis of cancer, or to the advanced stages of the disease. Our findings add to accumulating evidence than cancer does not necessarily result in psychiatric morbidity. Moreover, the discrepancy between the levels of distress in our sample and the levels of psychiatric morbidity, further heightens the importance of not inferring psychiatric disorder from elevated distress.

We set out to examine the psychological vulnerability of women anticipating genetic testing. What we have ended up demonstrating is the resilience of these women. We believe that attention can be profitably turned to better understanding why these women defy the not unreasonable assumption that they are a distressed, depressed, and anxious group. The experience of living with familial risk of cancer may well have had a resiliency-building effect that more than cancels any vulnerability associated with it. The particular aspects of this experience that cultivate resiliency and vulnerability need to be specified. As others have noted, adversity can produce resiliency as well as vulnerability, and women anticipating testing provide an excellent opportunity to study this (e.g., Schaeffer & Moos, 1992).

The suggestion from the Huntington disease studies is that persons who are at risk, and who have received positive results do not experience long-term negative psychological consequences. Despite these findings, there has been some tendency to dismiss this as denial. We take issue with this. Our findings of a lack of morbidity were based on validated measures of self-reported distress and carefully constructed interviews. We are concerned about pathologizing what appears to be good adjustment. The claim that this only represents psychological defensiveness or maladjustment needs to be substantiated with measures of these presumed processes and not simply established on the basis that these people are low on disorder and morbidity. We favor of a more charitable explanation of the low levels of distress and impairment in high risk women, and propose that for both affected and unaffected women, genetic testing is ostensibly an acute stressor, but it has the

prospect of resolving a longer term stress process by reducing uncertainty. Women who come from families where there is a high incidence of breast or ovarian cancer are likely to have preconceptions of their risk for breast cancer as well as of their options for dealing with it. Though we might presuppose that the anticipation of testing may be stressful, for some women it is an opportunity to confirm what they believe they already know and to organize their lives accordingly. For others there is the hope that contrary to their existing perception of risk for cancer, they will be found not to have the gene.

#### **CONCLUSION**

In the first year, our project made substantial progress in its implementation, confronting of a methodological and logistical challenges and its timely production of empirical results concerning the baseline adjustment of these high risk women anticipating the opportunity to receive genetic testing for risk of breast and ovarian cancer. The excellent mental health of these women is reassuring and shifts the focus of our research from efforts to predict baseline vulnerability to efforts to understand their resiliency in the face of their risk for breast cancer. As a byproduct of this effort, we were able to produce data from our affected women which are optimistic concerning the mental health of longer term cancer survivors.

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#### **APPENDICES**

Included with this report are copies of all of the questionnaires used to date:

Women's Health Study Questionnaire (Baseline Questionnaire)
Telephone Questionnaire
SCID Questionnaire
Interim Questionnaires (Affected and Unaffected Versions)
Spouse/Partner Questionnaires (Affected and Unaffected Versions)
Proband Pre-Results Questionnaires (Affected and Unaffected Versions)
Siblings Pre-Results Questionnaires
Proband Post-Results Questionnaire

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# WOMEN'S HEALTH STUDY QUESTIONNAIRE

Phone Number
Best time to reach you:  Weekdays  Weekday evenings  Weekend days  Weekend evenings  Anytime
Other:
Is there an alternative phone number where we may reach you

T

Today's Date	·			ID
Background Data				
A1. Date of Birth _	MonthI	Day	_Year	
A2. Ethnic Background:	White Hispanic Native American		Black Asian Other	
A3. Religion:	Catholic Jewish None		Protestant Other	
<ul> <li>A4. Are you currently (pleating)</li> <li>Single</li> <li>Not married, but living in marriage-like relationship</li> </ul>		☐ Mar ☐ Sep:		Widowed
A5a. If you are currently mar Month		e of your c	urrent marriage	?
A5b. Is this your first marriag	e? Yes $\square$	No 🗆		
A6. How many children do y	you have?			
A6a1. Ages of DAUG	HTERS: a d	b e	c f	
A6a2. Ages of SONS:	a d	b _ e	c f	
A6a. Number of child A6b. Number who are	ren living at home _ under age 6			
A7. Are you currently worki	ng for pay outside the	home?	Yes □	No 🗆
A8. If <u>yes</u> , about how many Less than 10	hours per week are your old 21-30	ou working	g for pay? 31-40 4	1 or more
A9. What is the highest level of Less than 9th gra  Completed high Completed college Completed gradu training	nde [ school [	☐ Dro ☐ Son	pped out of hig ne college ne graduate or p	
The following two questions Please check the appropriate be		e hope tha	t you will prov	vide this information
A10. What is your household Less than \$10,000 □ \$30,000 to \$39,999 □ \$60,000 to \$69,999	l's total income? (Che \$10,000 to \$19  \$40,000 to \$49  Greater than \$6	,999 ,999		to \$29,999 to \$59,999

A11.	How many people (ad	ults and childre	n) does t	his inco	me supp	ort? _				
B1. B2.	When were you first d Have your lymph node Yes □		1?		Month _ Do Not I					
В3.	Do you currently cons	ider yourself in No □		on?	Do Not l	Know				
B4.	What treatment(s) hav Chemotherapy Radiation Surgery		for breas Yes □ Yes □ Yes □		? No □ No □ No □					
B5.	Have you ever been di If yes, when?	agnosed with o	ovarian c _Year	ancer?	Y	les □			No 🗆	
В6.	If yes, when?  B6bOoph	Month orectomy (Removed) when? Month	al of lum	np from Year ovaries) Year	breast)		ase ch	eck all	that apply	).
	B6dHystered	when? Month ctomy (Remo when? Month al mastectomy	val of ute	erus) Year		s)				
	***************************************	when? Month				-,				
B7.	Before your diagnosis cancer, compared to Much		oman? (I	Please	circle on	ie)	were	to devel	op breast	
B8.	Before your diagnosis cancer, compared to Much	s of breast canc other women i Less Likely 1 2	er, how l n your f	amily?	id you thi ( <b>Please</b> of More Like 5	circle (	were one)	to devel	op breast	
B9.	Overall, what do you future?	believe your ri	sk is of o	levelop	ing breas	st cance	er agai	n <u>in th</u>	e near	
	0% 10%	20% 30%	40%	50%		70%	80%	90%	100%	
B10.	Overall, what do you your lifetime?  0% 10%	believe your r 20% 30%	isk is of 40%	develor 50%		st cand	er <i>aga</i> 80%	in <b>at s</b> o 90%	ome point i 100%	n_
B11.	Overall, what do you in the near future?	believe your ri	sk is of d	levelopi	ng a met	asis (ca	ancer s	preading	g to another	site)
	0% 10%	20% 30%	40%	50%	60%	70%	80%	90%	100%	

B12.			do you	believe	e your r	isk is o	f develo	oping a	metasis	at son	ie point	<u>t in your</u>
	<u>lifetim</u>	e: )%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
B13.	Overall,	what	do you	believe	your ri	sk is of	develop	oing car	ncer <b>un</b> ı	related	to your	breast
	cancer <u>i</u>	<u>n the</u> )%	near f 10%	<u>uture</u> ? 20%	30%	40%	50%	60%	70%	80%	90%	100%
B14.	Overall,	what	do you	believe	your ri	sk is of	develop	oing car	icer <b>un</b> i	related	to your	breast
	cancer g	at soi )%	me poi 10%	nt in y 20%	our life 30%	<u>etime</u> ? 40%	50%	60%	70%	80%	90%	100%
B15.	A medic risk for you have learn if	al test develo e beer	t may so oping a diagno cancer i	form of sed with set the ty	vailable breast a h breast pe that	that all and ova cancer runs in	ows son rian can , would	ne wom cer that you cor es? (Ple	runs in isider ta ease ch	familie king the eck <u>one</u>	s. Even e geneti e <b>respo</b>	though c test to nse).
			_		•		but I an	•				<b>'•</b>
			_			•	nmedia				•	
			-		_		but not i	•		onics a	valiaule	•
			-				ll take th		atery.			
					_			ie iesi.				
			•	probabl								
			I WIII (	<u>definitel</u>	<u>ty not</u> ta	ke the t	est.					
B16.	If you th so? (Pl		check To pla	all tha	t appl e future	y; som :					sons for	doing
				luce the		•					.•	
							areful al	bout do	ing self	examın	ations a	nd
			•	g regula		•						
							ether to		ventive	surgery	•	
							ily plan	•				
						•	be trans		to my cl	hildren.		
							get testi	•				
			Other	(describ	e)							
B17.	If you <b>d not</b> doi											asons for 1).
			I am h	appier i	not kno	wing.						
			It wou	ld be to	o upset	ting to l	earn tha	t I am a	t high r	isk for t	reast ca	incer.
			I belie	ve I alre	eady kn	ow wha	t my ris	k for br	east car	ncer is.		
			There	would i	not be n	nuch I c	ould do	if I fou	nd out l	l was at	high ris	sk for
			breast	cancer.								
			I do no	ot feel a	ble emo	tionally	to deal	with te	sting.			
			Family	y memb	ers do r	not wan	t me to g	get testi	ng.			
			Risk to	o my in	surance	covera	ge.					

For the next questions we are interested in how people close to you respond to you when you are in need of support or reassurance. In answering the questions in the <u>first column</u>, please keep in mind a female family member who may be at risk for breast cancer <u>with whom you are closest</u>. Answer the questions in the <u>second column</u> keeping in mind <u>your spouse or intimate partner</u>. If you do not have a spouse or intimate partner, please leave the second column blank. For the <u>third column</u>, please keep in mind <u>another family member or friend to whom you are closest</u>.

		Female Family Member at Risk for Breast Cancer	Spouse/Partner	Another Family Member/ Friend
C1.	Was physically present when you needed them.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C2.	Told you what he/she did in a similar situation.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C3.	Did activities to help you get your mind off things.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C4.	Told you that the things you talk about are privatejust between the two of you.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C5.	Suggested some action you should take.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C6.	Comforted you by showing you physical affection.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C7.	Listened to you talk about your private feelings.	☐ Yes ☐ No	☐ Yes ☐ No	□ Yes □ No
C8.	Agreed that what you want to do is right.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C9.	Told you how he/she felt in a similar situation.	☐ Yes ☐ No	□ Yes □ No	□ Yes □ No
C10.	Let you know that he/she will always be around if you need assistance.	□ Yes □ No	□ Yes □ No	□ Yes □ No
C11.	Gave you feedback on how you were doing without saying it was good or bad.	□ Yes □ No	□ Yes □ No	☐ Yes ☐ No
	Pitched in and helped you do things that needed to get done.	☐ Yes ☐ No	□ Yes □ No	□ Yes □ No
	Intruded into your personal feelings and concerns.	☐ Yes ☐ No	□ Yes □ No	□ Yes □ No
	Gave you unsolicited advice.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
	Attempted to make unwanted contact.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
	Discouraged you from discussing your feelings and concerns.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
	Minimized your worries or concerns.	☐ Yes ☐ No	□ Yes □ No	□ Yes □ No
	Rejected you for displaying emotional upset.		□ Yes □ No	☐ Yes ☐ No
	Insisted that you remain upbeat and optimistic.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C20.	Let you down when you were counting on him/her.	☐ Yes ☐ No	□ Yes □ No	☐ Yes ☐ No
C21.	Is there anyone in your life with whom you	i can share your mos	st private feeling	gs without

C21.	Is there anyone in holding back?	your life with	n whom	you can s	share you	r most pri	vate feeling	s without
	□ Ves	Г	∃ No					

C21a.	you are married or living with a par lings with this partner without holding ba ☐ Yes ☐ No		an yo	ou share your most private
D1.	we any of the events listed happened to yoply)	ou in <u>t</u>	he pa	st six months? (Check All That
a.	You retired or were fired or laid off from work.	g.		A close family member was seriously ill or injured.
b.	You were unemployed and looking for work.	h.		You had a marital separation or divorce.
c.	Your spouse retired or was fired or laid off from work.	i.		You had serious troubles with relatives or close friends.
d	Your spouse was unemployed and looking for work.	j.		Your spouse had troubles difficulties with relatives or close friends.
e.	You had problems with the police or court.	k.		A close family member died. A close friend or relative died.
f.	You got into serious financial difficulties	1. m.		You were seriously ill or injured.

For each of these statements, please indicate the extent to which you agree or disagree by circling the appropriate number. Try to be as accurate and as honest as you can, and try not to let your answer to one question influence your answers to other questions. There are no right or wrong answers. We are only interested in your opinions.

		Stro: Disa		Neutral		Strongly Agree
E1.	In uncertain times, I usually expect the best.	1	2	3	4	5
E2.	It's easy for me to relax.	1	2	3	4	5
E3.	If something can go wrong for me, it will.	1	2	3	4	5
E4.	I always look on the bright side of things.	1	2	3	4	5
E5.	I'm always optimistic about my future.	1	2	3	4	5
E6.	I enjoy my friends a lot.	1	2	3	4	5
E7.	It's important for me to keep busy.	1	2	3	4	5
E8.	I hardly ever expect things to go my way.	1	2	3	4	5
E9.	Things never work out the way I want them to	1	2	3	4	5
E10.	I don't get upset too easily.	1	2	3	4	5
E11.	I'm a believer in the idea that "every cloud has a silver lining".	1	2	3	4	5
E12.	I rarely count on good things happening to me.	1	2	3	4	5

Below is a list of words which people might use to describe themselves. You are asked to rate them <u>twice</u>. First, please indicate for each word <u>how well it describes you</u> and second, <u>how much it matters to you</u> using the following scale.

Ex	1 2 stremely Very mucl	3 n Somewhat No			Not	4 very	well	5 Not at all				
		DESCRIBES ME					M	IATT	ERS	TO M	<u>(E</u>	
F1.	Involved in family	1	2	3	4	5	1	2	3	4	5	
F2.	Aware of being a woman	1	2	3	4	5	1	2	3	4	5	
F3.	Involved in paid work	1	2	3	4	5	1	2	3	4	5	
F4.	Being a mother	1	2	3	4	5	1	2	3	4	5	
F5.	Involved in organization/volunteer work	1	2	3	4	5	1	2	3	4	5	
F6.	Being a grandmother	1	2	3	4	5	1	2	3	4	5	
F7.	Physically attractive	1	2	3	4	5	1	2	3	4	5	
F8.	Being a wife	1	2	3	4	5	1	. 2	3	4	5	
F9.	Healthy	1	2	3	4	5	1	2	3	4	5	
F10.	Being a daughter	1	2	3	4	5	1	2	3	4	5	
F11.	Intelligent	1	2	3	4	5	1	2	3	4	5	
F12.	Able to cope	1	2	3	4	5	1	2	3	4	5	
F13.	Spiritual or religious	1	2	3	4	5	1	2	3	4	5	
F14.	Outgoing	1	2	3	4	5	1	2	3	4	5	
F15.	Independent	1	2	3	4	5	1	2	3	4	5	
F16.	Realistic	1	2	3	4	5	1	2	3	4	5	
F17.	Active	1	2	3	4	5	1	2	3	4	5	
F18.	Loved	1	2	3	4	5	1	2	3	4	5	
F19.	Caring	1	2	3	4	5	1	2	3	4	5	
F20.	Depressed	1	2	.3	4	5	1	2	3	4	5	

In the next table, we would like you to first rate how well you think each word will describe you <u>in</u> <u>the future</u>. and then, indicate how important it is for you to see yourself this way <u>in the future</u>.

1 2 3 4 5
Extremely Very much Somewhat Not very well Not at all

	·	WILL DESCRIBE YOU						IMPORTANT FOR  YOU TO SEE  YOURSELF THIS WAY IN FUTURE				
<b>G</b> 1.	Involved in family	1	2	3	4	5	1	2	3	4	5	
G2.	Aware of being a woman	1	2	3	4	5	1	2	3	4	5	
G3.	Involved in paid work	1	2	3	4	5	1	2	3	4	5	
G4.	Being a mother	1	2	3	4	5	1	2	3	4	5	
G5.	Involved in organization/volunteer work	1	2	3	4	5	1	2	3	4	5	
<b>G</b> 6.	Being a grandmother	1	2	3	4	5	1	2	3	4	5	
<b>G</b> 7.	Physically attractive	1	2	3	4	5	1	2	3	4	5	
G8.	Being a wife	1	2	3	4	5	1	2	3	4	5	
<b>G</b> 9.	Healthy	1	2	3	4	5	1	2	3	4	5	
G10.	Being a daughter	1	2	3	4	5	1	2	3	4	5	
<b>G</b> 11.	Intelligent	1	2	3	4	5	1	2	3	4	5	
G12.	Able to cope	1	2	3	4	5	1	2	3	4	5	
G13.	Spiritual or religious	1	2	3	4	5	1	2	3	4	5	
G14.	Outgoing	1	2	3	4	5	1	2	3	4	5	
G15.	Independent	1	2	3	4	5	1	2	3	4	5	
G16.	Realistic	1	2	3	4	5	1	2	3	4	5	
G17.	Active	1	2	3	4	5	1	2	3	4	5	
G18.	Loved	1	2	3	4	5	1	2	3	4	5	
G19.	Caring	1	2	3	4	5	1	2	3	4	5	
G20.	Depressed	1	2	3	4	5	1	2	3	4	5	

The following questions apply to persons who are <u>married or living with a partner</u>. Please complete them if you are. <u>If you are not married or living with a partner</u>, please skip to Section I on page 13.

Most persons have disagreements in their relationships. Please indicate, with check marks, on the following list, the extent of agreement or disagreement experienced between you and your partner **DURING THE PAST MONTH**.

		Always Agree	Almost Always Agree	Occa- sionally Disagree	Fre- quently Disagree	Almost Always Disagree	Always Disagree
H1.	Handling family finances						
H2.	Matters of recreation						
Н3.	Religious matters						
H4.	Demonstration of affection						
H5.	Friends						
Н6.	Sex relations						
H7.	Conventionality (correct or proper behavior						
Н8.	Philosophy of life						
Н9.	Ways of dealing with parents or in-laws						
H10.	Aims, goals, and things believed important						
H11.	Amount of time spent together						
H12.	Making major decisions						
H13.	Household tasks						
H14.	Leisure time interests and activities						
H15.	Career decisions						

		All of the time	Most of the time	More often than most	Occa- sionally	Rarely	Never
H16.	How often do you discuss or have you considered divorce, separation, or terminating your relationship?						
H17.	How often do you or your mate leave the house after a fight?						

		All of the time	Most of the time	More often than most	Occa- sionally	Rarely	Never
H19.	Do you confide in your mate?						
H20.	Do you ever regret that you married (or lived together)?						
H21.	How often do you and your partner quarrel?						
H22.	How often do you and your mate "get on each other's nerves?"						
		Every Day	Almost Every Day	Occa- sionally	Rarely	Never	
H23.	Do you kiss your mate?						
	·	All of Them	Most of Them	Some of Them	Very few of Them	None of Them	
H24.	Do you and your mate engage in outside interests together?						
$\mathbf{H}^{\prime\prime}$	often would you say the follow:	my evems					
	Have a stimulating exchange	Never	Less than once a month	About twice a month	About twice a week	Once a day	More Often
H25.	Have a stimulating exchange of ideas.		Less than once a	About twice a	About twice a	Once a	· ·
H25. H26.	Have a stimulating exchange of ideas.  Laugh together.		Less than once a	About twice a	About twice a	Once a	· ·
H25. H26. H27.	Have a stimulating exchange of ideas.		Less than once a	About twice a	About twice a	Once a	· ·
H25. H26. H27. H28. These item b	Have a stimulating exchange of ideas.  Laugh together.  Calmly discuss something.	Never	Less than once a month	About twice a month	About twice a week	Once a day	Often
H25. H26. H27. H28. These item b month	Have a stimulating exchange of ideas.  Laugh together.  Calmly discuss something.  Work together on a project.  are some things couples somethelow caused differences of opin. (Check yes or no).	Never	Less than once a month	About twice a month	About twice a week	Once a day	Often
H25. H26. H27. H28. These item b month	Have a stimulating exchange of ideas.  Laugh together.  Calmly discuss something.  Work together on a project.  are some things couples somethelow caused differences of opin. (Check yes or no).	Never imes agree	Less than once a month	About twice a month	About twice a week	Once a day	Often
H25. H26. H27. H28. These item b month H29. H30. H31. middl	Have a stimulating exchange of ideas.  Laugh together.  Calmly discuss something.  Work together on a project.  are some things couples somethelow caused differences of opin. (Check yes or no).  Being too tired for sex.	imes agreenions or w	Less than once a month  e and sometrere problem  t degrees of happiness	About twice a month  imes disagns in your to No  No happiness of most rel	About twice a week  ree upon. relationsh	Once a day  Indicate if cip during the delationship.	Often  either past  The ircle the

H32.	Please check <u>one</u> of the following statements which best describes how you feel about the <b>future</b> of your relationship.								
		I want desperately for my relationship to succeed, and would							
•		go to almost any length to see that it does.							
		I want very much for my relationship to succeed, and will do all I can to see that it does.							
		I want very much for	my relationship to	succeed, and wil	<u>ll do</u>				
		my fair share to see t	hat it does.						
		It would be very nice	e if my relationship	succeeded, but I	can't				
		do much more than I	am doing now to	help it succeed.					
		It would be nice if it	succeeded, but I re	fuse to do any mo	<u>ore</u>				
		than I am doing now to keep the relationship going.							
	My relationship can never succeed, and there is no more that I								
	can do to keep the relationship going.								
I1.	In general, would you say your health is:								
	☐ Excellent	☐ Very Good	$\square$ Good	☐ Fair	□ Poor				
I2.	Compared to one year ago, how would you rate your health in general now?(Check one)								
		Much better now than one year ago							
		Somewhat better now than one year ago							
		About the same as one year ago							
		Somewhat worse now than one year ago							
		Much worse than one year ago							

13. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much? *Please mark the appropriate box to indicate your response.* 

		YES, limited a lot.	YES, limited a little.	NO, not limited at all.
a.	Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports.			
b.	Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.			
c.	Lifting or carrying groceries.			
d.	Climbing several flights of stairs.			-
e.	Climbing one flight of stairs.			
f.	Bending, kneeling, or stooping.			
g.	Walking more than a mile.			
h.	Walking several blocks.			
i.	Walking one block.			
j.	Bathing or dressing yourself.	W		
I4.	During the past 4 weeks, have other regular daily activities as a result. Cut down the amount of the control of	sult of your physical	health?	

I5.	or other regular daily	During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?  I5a. Cut down the amount of time you spent on work □ Yes □ No								
		I5a. Cut down the amount of time you spent on work $\Box$ Yes or other activities.								
	I5b. Accomplished	less than you	u would like	•	☐ Yes		□No			
	I5c. Didn't do work		ivities as		$\square$ Yes		□No			
	carefully as us	ual.								
I6.	<b>During the past 4 weeks</b> , to what extent has your physical health or eproblems interfered with your normal social activities with family, friend groups?									
	$\square$ Not at all	☐ Slightly	☐ Modei	rately $\Box$	Quite a bit	☐ Extrem	iery			
I7.	How much bodily paid □ Not at all	in have you  ☐ Slightly	_	_	weeks? Quite a bit	☐ Extrem	nely			
I8.	During the past 4 we (including both work of □ Not at all	outside the ho		isework)?	rith your nor Ouite a bit	rmal work      □ Extrem	nelv			
<b>I</b> 9.	These questions are ab 4 weeks. For each que you have been feeling the appropriate box to	estion, pleas . How mucl	e give the or h of the time	ne answer tha	at comes clo	sest to the w	/ay a			
		All of the	Most of	A good bit	Some of	A little of	None of			
		time	the time	of the time	the time	the time	the time			
a.	Did you feel full of pep?									
b.	Have you been a very nervous person?		:							
c.	Have you felt so down in the dumps that nothing could cheer you up?									
d.	Have you felt calm and peaceful?			:						
e.	Did you have a lot of energy?									
f.	Have you felt downhearted and blue?									
g.	Have you been a happy person?									
	Did you feel tired?					]				

I10.	During the pa							
☐ All the tir	of $\square$ Mos		☐ A good bit of the time	$f \square S$	Some of the time	•	le of 🗆 No	
I11.	How TRUE or	FALSE	is each of the	following	stateme	nts for you	?	
		Γ	Definitely True	Mostly True		Don't Know	Mostly False	Definite False
easier	em to get sick a l than other peopl							
	n as healthy as dy I know.							
	pect my health to	get						
worse								
d. My	health is excelle	nt.						
	In the past 6 m lue, or depressed sually liked to do	or in who for fun?	nich you lost al	ll interest ir □ Yes	things:	like work o Io	r hobbies or t	ĥings
	I12a. If yes, t  ☐ Yes		s such a two-w □ No	eek penou	i, uiu yo	ur work or	iciauonsinps	Suffer?
			s such a two-w	eek period	did vo	i get collins	eling or	
	•	therapy?	s such a two w	cox poriou	, ala yo	a got couns	cinig or	
	□ Yes		□ No					
		_	ch a two-week	period, did	vou get	medication	for this cond	ition?
	□ Yes		□ No	<b>r</b>	7 8			
I13.	Are you curre	ntly rece	iving counseli	ng or psych	otherap	y or medica	ation for depre	ession or
	emotional prob	•	☐ Yes		•	,	•	
J1.	How often do y	ou have	a drink contain	ning alcoho	1?			
	☐ Neve	er [	☐ Monthly or l	ess 🗆 🗆	Two to fo	our times a	month	
	☐ Two	to three	times a week		Four or 1	more times	a week	
J2.	How many drin  ☐ 1 or		_	do you have □ 5 or 6	e on a ty □ 7 to		then you are d	rinking?
J3.	Have you ever ☐ Yes	-	should cut dov □ No	vn on your	drinking	;?		
J4.	Have people ar  ☐ Yes	•	ou by criticizir □ No	ng your drir	ıking?			
J5.	Have you ever ☐ Yes		or guilty about □ No	drinking?				
J6.	Have you ever hangover?  ☐ Yes		lrink first thing □ No	g in the mor	rning to	steady your	nerves or get	rid of a

Listed Below Are Some Symptoms Of Strain That People Sometimes Have. Please Read Each One Carefully And Check The Answer Which Best Reflects How Much That Symptom Has Bothered You During the <u>Past Three Months</u>.

	Not at all	A little	Ouite a bit	Extremely
K1. Suddenly scared for no reason				
K2. Feeling fearful	<del> </del>			
K3. Faintness, dizziness, or weakness				
K4. Nervousness or shakiness inside				
K5. Heart pounding or racing				:
K6. Trembling				
K7. Feeling tense or keyed up				
K8. Headaches				
K9. Spells of terror or panic				****
K10. Feeling restless, can't sit still				
K11. Feeling low in energyslowed down				
K12. Blaming yourself for things				
K13. Crying easily				
K14. Loss of sexual interest or pleasure				
K15. Poor appetite				
K16. Difficult falling asleep, staying asleep				
K17. Feeling hopeless about the future				
K18. Feeling blue				
K19. Feeling lonely				
K20. Feeling trapped or caught				
K21. Worrying too much about things				
K22. Feeling no interest in things				
K23. Thoughts of ending your life				
K24. Feeling everything is an effort				
K25. Feelings of worthlessness				

L1.		ne that you are afraid of the dentist and have to get some dental work done.  ollowing would you do? Check all of the statements that might apply to
		I would ask the dentist exactly what he was going to do.
		I would take a tranquilizer or have a drink before going.
		I would try to think about pleasant memories.
		I would want the dentist to tell me when I would feel pain.
		I would try to sleep.
		I would watch all the dentist's movements and listen for the sound of the drill.
	-	I would watch the flow of water from my mouth to see if it contained blood.
		I would do mental puzzles in my mind.
L2.	Vividly imagin building. Which apply to you.	ne that you are being held hostage by a group of armed terrorists in a public ch of the following would you do? Check all of the statements that might
		I would sit by myself and have as many daydreams and fantasies as I could.
		I would stay alert and try to keep myself from falling asleep.
		I would exchange life stories with the other hostages.
		If there was a radio present, I would stay near it and listen to the bulletins
		about what the police were doing.
	<del></del>	I would watch every movement of my captors and keep an eye on their weapons.
		I would try to sleep as much as possible.
		I would think about how nice it's going to be when I get home.
		I would make sure I knew where every possible exit was.
L3.	department at work for the pa	ne that, due to a large drop in sales, it is rumored that several people in your work will be laid off. Your supervisor has turned in an evaluation of your ast year. The decision about lay-off's has been made and will be announced as. Check all of the statements that might apply to you.  I would talk to my fellow workers to see if they knew anything about what the supervisor's evaluation of me said.
		I would review the list of duties for my present job and try to figure out if I had fulfilled them all.
		I would go to the movies to take my mind off things.
		I would try to remember any arguments or disagreements I might have had
		with the supervisor that would have lowered his opinion of me.
		I would push all thoughts of being laid off out of my mind.
		I would tell my spouse that I'd rather not discuss my chances of being laid off.
		I would try to think which employees in my department the supervisor
		might have thought had done the worst job.
		I would continue doing my work as if nothing special was happening.

16
Vividly imagine that you are on an airplane, 30 minutes from your destination, when the plane unexpectedly goes into a deep dive and then suddenly levels off. After a short time the pilot announces that nothing is wrong, although the rest of the ride may be rough. You, however, are not convinced that all is well. Check all of the statements that might apply to you.
I would carefully read the information provided about safety features in th
plane and make sure I knew where the emergency exits were.
I would make small talk with the passenger beside me.
I would watch the end of the movie, even if I had seen it before.
I would call for the stewardess and ask her exactly what the problem was
I would order a drink or tranquilizer from the stewardess.
I would listen carefully to the engines for unusual noises and would watch
the crew to see if their behavior was out of the ordinary.
I would talk to the passenger beside me about what might be wrong.
I would settle down and read a book or magazine or write a letter.

Please indicate how much you agree with the following statements. L5.

		Strongly Disagree				Strongly Agree	
a.	If you don't have your health, you don't have anything.	1	2	3	4	5	
b.	There are many things I care about more than my health.	1	2	3	4	5	
c.	Good health is of only minor importance in a happy life.	1	2	3	4	5	
d.	There is nothing more important than good health.	1	2	3	4	5	

Please indicate the extent to which each of the following items describes your current family.

		Strong Disagn				rongly Agree
M1.	Planning family activities is difficult because we misunderstand each other.	1	2	3	4	5
M2.	In times of crisis we can turn to each other for support.	1	2	3	4	5
M3.	We cannot talk to each other about the sadness we feel.	1	2	3	4	5
M4.	Individuals are accepted for what they are.	1	2	3	4	5
M5.	We avoid discussing our fears and concerns.	1	2	3	4	5
M6.	We can express feelings to each other.	1	2	3	4	5
M7.	There are lots of bad feelings in the family.	1	2	3	4	5
M8.	We feel accepted for what we are.	1	2	3	4	5
M9.	Making decisions is a problem for our family.	1	2	3	4	5
M10.	We are able to make decisions about how to solve problems.	1	2	3	4	5
M11.	We don't get along well together.	1	2	3	4	5
M12.	We confide in each other.	1	2	3	4	5

THANK YOU VERY MUCH.

1 1	i 1			l í
1 1				1
I I	1 1			1
1 1	1 3	.		i I
L. 1	1 1			





## WOMEN'S HEALTH STUDY QUESTIONNAIRE

ID		

Bac	kgr	ound	Data

A1.	Date of Birth	MonthD	ay _	Year	
A2.	Ethnic Background:	White Hispanic Native American		Black Asian Other	
A3.	Religion:	Catholic Jewish None		Protestant Other	
A4.	Are you currently (please	check one)?		Single Married Not married, but live marriage-like relation Separated Divorced Widowed	
A5a.	If you are currently married  Month Ye		of yo	our current marriage?	
A5b.	Is this your first marriage?	Yes □ N	Го		
A6.	How many children do you A6a. Number of children A6b. Number who are un	living at home			
A7.	Are you currently working	for pay outside the h	ome'	?	
	Yes □ No				
A8.	If yes, about how many ho	urs per week are yo	u wo	rking for pay?	
	Less than 10 10-2	0 21-30		31-40 41	or more

A9.	What is the h	ighest level of education you have completed? (Cneck one)
		Less than 9th grade
		Dropped out of high school
		Completed high school
		Some college
		Completed college
		Some graduate or professional training
		Completed graduate or professional training
The f	following two	o questions are optional, but we hope that you will provide this information. ppropriate box. (Check one)
A10.	What is you	ur household's total income? (Check one)
		Less than \$10,000
		\$10,000 to \$19,999
		\$20,000 to \$29,999
		\$30,000 to \$39,999
		\$40,000 to \$49,999
		\$50,000 to \$59,999
		\$60,000 to \$69,999
		Greater than \$69,999
A11.	How many	people (adults and children) does this income support?

SECTION 1	B
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B1. F	lave yo	ou ever	been dia	agnosed	with b	reast car	ncer?	Yes		No [		
B2. I	Have yo	ou ever	been dia	ignosed	with o	varian (	cancer?	Yes		No [		
<b>B</b> 3. E	Iave yo	ou ever	had any	of the	follow	ing sur	gical pro	ocedure	s? (Ple	ase che	ck all t	hat apply).
	_Lump	pectomy breast	y (Remo	oval of l	ump			Oop	horecto	omy (Re	emoval	of ovaries)
×		iteral m	astecton ast)	ny (Rer	noval			Hys	terector	ny (Re	moval c	of uterus)
		ateral m h breas	nastector ts)	ny (Re	moval c	of						
B4.	Complikely	pared to are yo	o the <u>ave</u> u to dev	erage w elop bre	oman, l east can	now cer?			h Less cely	2 3	4	Much More Likely 5
B5.	Com	pared to likely a	o <u>other v</u> re you to	women i o develo	in your op breas	family, st cancer	r?		h Less cely	2 3	4	Much More Likely 5
B6.	Over <u>futu</u>		at do yo	u believ	e your	risk to l	be of de	velopin	g breas	t cancer	<u>in the r</u>	<u>iear</u>
	0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%	
B7.	Over	all, wha	at do yo <b>etime</b> ?	u believ	ve your	risk to	be of de	velopin	g breas	t cancer	at som	<u>e point</u>
	0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%	
B8.	risk f	or deve	cloping a	a form o	of breas	t and ov	zarian ca	incer tha	at runs :	women t in famili se chec	es. Kno	their owing this, what response).
		I	will def	initely	take the	test im	mediatel	y when	it becon	mes avai	lable.	
			will de	-								
			-	-						nes avai	lable.	
			will pro						ly.			
		I	am und	ecided '	whether	: I will t	ake the	test.				

	I will probably not take the test.
	I will definitely not take the test.
B9.	If you think you will probably or definitely take the test, what are your reasons for doing so? (Please check all that apply).
	To plan for the future.
	To reduce the uncertainty.
	To know I have to be more careful about doing breast self examinations and getting
	regular checkups.
	To make decisions about whether to get preventive surgery.
	To make decisions about family planning.
	To find out the risk that may be transmitted to my children.
	Family members want me to get testing.
	Other (describe)

B10.	If you do I doing so?	not think you will probably or definitely take the test, what are your reasons for not (Please check all that apply).
		I am happier not knowing.
		It would be too upsetting to learn that I am at high risk for breast cancer.
		I believe I already know what my risk for breast cancer is.
		There would not be much I could do if I found out I was at high risk for breast cancer.
		I do not feel able emotionally to deal with testing.
		Family members do not want me to get testing.
		Risk to my insurance coverage.

B11. If you were to take the test and find out that you were not at high risk for breast cancer, what would you expect your reactions to be?

		Strong Disagr				rongly Agree
a.	I would feel wonderful.	1	2	3	4	5
b.	I would feel I had been told what I knew all along.	1	2	3	4	5
c.	I would feel relieved.	1	2	3	4	5
d.	I would not believe the results.	1	2	3	4	5
e.	I would fall apart emotionally.	1	2	3	4	5
f.	I would feel guilty.	1	2	3	4	5
g.	I would still feel anxious.	1	2	3	4	5
h.	I would feel angry.	1	2	3	4	5
i.	I would feel prepared for the future.	1	2	3	4	5
j.	I would feel I had done all I needed to do.	1	2	3	4	5

B12. If you were to take the test and find out that you were at high risk for breast cancer, what would you expect your reactions to be?

		Strong Disagi	rly ree		St A	rongly Igree
a.	I would feel relieved about being more certain.	1	2	3	4	5
b.	I would feel I had been told what I knew all along.	1	2	3	4	5
c.	I would not believe the results.	1	2	3	4	5

			Strongly Disagree			Strongly Agree	
d.	I would feel guilty.	1	2	3	4	5	
e.	I would be depressed.	1	2	3	4	5	
f.	I would feel worried about the future.	1	2	3	4	5	
g	I would just fall apart emotionally.	1	2	3	4	5	
h.	I would feel anxious.	1	2	3	4	5	
i.	I would feel angry.	1	2	3	4	5	

B13. To what extent do you agree with the following statements?

	B13. To what extent do you agree with the following	Strongly Disagree				Strongly Agree	
a.	Mammography is effective in the early detection of breast cancer.	1	2	3	4	5	
b.	Breast cancer that is detected early is curable.	1	2	3	4	5	
c.	Mammography can detect lumps that cannot be felt by you or your doctor.	1	2	3	4	5	
d.	If more women went for breast screening, there would be fewer deaths from breast cancer.	1	2	3	4	5	
e.	My health is too good to consider thinking that I might get breast cancer.	1	2	3	4	5	
f.	If a lump is found in your breast, it is usually too late to do anything about it.	1	2	3	4	5	
g.	Whenever I hear of a friend/relative or public figure getting breast cancer I realize that I could get it too.	1	2	3	4	5	
h.	If I examine my own breasts regularly, I might find a lump sooner than if I wait to go for screening.	1	2	3	4	5	
i.	There are so many things that could happen to me that it is pointless to think about breast cancer.	1	2	3	4	5	
j.	Even though it is a good idea, I find examination of my breasts an embarrassment.	1	2	3	4	5	
k.	The older I get, the more I think about the possibility of getting breast cancer.	1	2	3	4	5	
1.	Going for screening has increased my worry about breast cancer.	1	2	3	4	5	
m.	If I was found to have breast cancer, the chances of it being cured are high.	1	2	3	4	5	

		Not A	t All		All Th	e Time
B15.	How often do you worry about developing breast cancer?	1	2	3	4	5
B16.	To what extent do any worries you have about breast cancer interfere with every day life?	1	2	3	4	5

For the next questions we are interested in how people close to you respond to you when you are in need of support or reassurance. In answering the questions in the <u>first column</u>, please keep in mind the female family member at similar risk for breast cancer <u>with whom you are closest</u>. Answer the questions in the <u>second column</u> keeping in mind <u>your spouse or intimate partner</u>. If you do not have a spouse or intimate partner, please leave the second column blank. For the <u>third column</u>, please keep in mind <u>another family member or friend to whom you are closest</u>.

·		Female Family Member at Risk for Breast Cancer	Spouse/Partner	Another Family Member/ Friend
C1.	Was physically present when you needed them.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C2.	Told you what he/she did in a similar situation.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C3.	Did activities to help you get your mind off things.	☐ Yes ☐ No	☐ Yes ☐ No	□ Yes □ No
C4.	Told you that the things you talk about are privatejust between the two of you.	☐ Yes ☐ No	☐ Yes ☐ No	□ Yes □ No
<u>C5.</u>	Suggested some action you should take.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
<u>C6.</u>	Comforted you by showing you physical affection.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C7.	Listened to you talk about your private feelings.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
<del>C</del> 8.	Agreed that what you want to do is right.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
<del>C</del> 9.	Told you how he/she felt in a similar situation.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C10.	Let you know that he/she will always be	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No

	Female Family Member at Risk for Breast Cancer	Spouse/Partner	Another Family Member/ Friend
C11. Gave you feedback on how you were without saying it was good or bad.	e doing Yes No	☐ Yes ☐ No	☐ Yes ☐ No
C12. Pitched in and helped you do things to needed to get done.	that	☐ Yes ☐ No	☐ Yes ☐ No
C13. Intruded into your personal feelings concerns.	and ☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C14. Gave you unsolicited advice.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C15. Attempted to make unwanted contact	t.	☐ Yes ☐ No	☐ Yes ☐ No
C16. Discouraged you from discussing yo feelings and concerns.	our	☐ Yes ☐ No	☐ Yes ☐ No
C17. Minimized your worries or concerns		☐ Yes ☐ No	☐ Yes ☐ No
C18. Rejected you for displaying emotions	al upset. □ Yes □ No	☐ Yes ☐ No	☐ Yes ☐ No
C19. Insisted that you remain upbeat and optimistic.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C20. Let you down when you were counting on him/her.	ing ☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C21. Is there anyone in your life with w back?  □ yes □ no	vhom you can share your m	nost private feel	ings without holding
C21a. If you are married or living withis partner without holding back?   yes  no	ith a partner, can you sh	are your most p	private feelings with

D1.	Have any of the events listed happened	to you in the pa	ast six months? (Check All That Apply)
a.	You retired or were fired or laid off from work.	g.	☐ A close family member was seriously ill or injured.
b.	You were unemployed and looking for work.	or h.	<ul> <li>You had a marital separation or divorce.</li> </ul>
c.	Your spouse retired or was fired or laid off from work.	i.	☐ You had serious troubles with relative or close friends.
d	<ul> <li>Your spouse was unemployed and looking for work.</li> </ul>	j.	☐ Your spouse had troubles difficulties with relatives or close friends.
e.	☐ You had problems with the police or	k.	☐ A close family member died.
0.	court.	1.	☐ A close friend or relative died.
f.	☐ You got into serious financial difficulties	m.	☐ You were seriously ill or injured.

For each of these statements, please indicate the extent to which you agree or disagree by circling the appropriate number. Try to be as accurate and as honest as you can, and try not to let your answer to one question influence your answers to other questions. There are no right or wrong answers. We are only interested in your opinions.

		Strong Disagr		Neutral		rongly Agree
E1.	In uncertain times, I usually expect the best.	1	2	3	4	5
E2.	It's easy for me to relax.	1	2	3	4	5
E3.	If something can go wrong for me, it will.	1	2	3	4	5
E4.	I always look on the bright side of things.	1	2	3	4	5
E5.	I'm always optimistic about my future.	1	2	3	4	5
E6.	I enjoy my friends a lot.	1	2	3	4	5
E7.	It's important for me to keep busy.	1	2	3	4	5
E8.	I hardly ever expect things to go my way.	1	2	3	4	5
E9.	Things never work out the way I want them to	1	2	3	4	5
E10.	I don't get upset too easily.	1	2	3	4	5
E11.	I'm a believer in the idea that "every cloud has a silver lining".	1	2	3	4	5
E12.	I rarely count on good things happening to me.	1	2	3	4	5

Below is a list of words which people might use to describe themselves. You are asked to rate them <u>twice</u>. First, please indicate for each word <u>how well it describes you</u> and second, <u>how much it matters to you</u> using the following scale.

Ex	1 2 stremely Very much		3 Somew	hat	Not	4 very	5 well Not at all		11		
			DESC	CRIBES	S ME			MATT	ERS I	O ME	
F1.	Involved in family	1	2	3	4	5	1	2	3	4	5
F2.	Aware of being a woman	1	2	3	4	5	1	2	3	4	5
F3.	Involved in paid work	1	2	3	4	5	1	2	3	4	5
F4.	Being a mother	1	2	3	4	5	1	2	3	4	5
F5.	Involved in organization/volunteer work	1	2	3	4	5	1	2	3	4	5
F6.	Being a grandmother	1	2	3	4	5	1	2	3	4	5
F7.	Physically attractive	1	2	3	4	5	1	2	3	4	5
F8.	Being a wife	1	2	3	4	5	1	2	3	4	5
F9.	Healthy	1	2	3	4	5	1	2	3	4	5
F10.	Being a daughter	1	, 2	3	4	5	1	2	3	4	5
F11.	Intelligent	1	2	3	4	5	1	2	3	4	5
F12.	Able to cope	1	2	3	4	5	1	2	3	4	5
F13.	Spiritual or religious	1	2	3	4	5	1	2	3	4	5
F14.	Outgoing	1	2	3	4	5	1	2	3	4	5
F15.	Independent	1	2	3	4	5	1	2	3	4	5
F16.	Realistic	1	2	3	4	5	1	2	3	4	5
F17.	Active	1	2	3	4	5	1	2	3	4	5
F18.	Loved	1	2	3	4	5	1	2	3	4	5
F19.	Caring	1	2	3	4	5	1	2	3	4	5
F20.	Depressed	1	2	3	4	5	1	2	3	4	5

In the next table, we would like you to first rate how well you think each word will describe you <u>in the future</u>. and then, indicate how important it is for you to see yourself this way <u>in the future</u>.

T 1	2	3	4	5
Extremely	Very much	Somewhat	Not very well	Not at all

										R YOU	
		$\underline{W}$	ILL D	<u>ESCRI</u>	BE YO	<u> </u>	SEE			THIS	<u>WAY</u>
							1		FUTU 2		5
G1.	Involved in family	1	2	3	4	5	1	2	3	4	
G2.	Aware of being a woman	1	2	3	. 4	5	1	2	3	4	5
G3.	Involved in paid work	1	2	3	4	5	1	2	3	4	5
G4.	Being a mother	1	2	3	4	5	1	2	3	4	5
G5.	Involved in organization/	1	2	3	4	5	1	2	3	4	5
	volunteer work										
G6.	Being a grandmother	1	2	3	4	5	1	2	3	4	5
<b>G</b> 7.	Physically attractive	1	2	3	4	5	1	2	3	4	5
G8.	Being a wife	1	2	3	4	5	1	2	3	4	5
<b>G</b> 9.	Healthy	1	2	3	4	5	1	2	3	4	5
G10.	Being a daughter	1	2	3	4	5	1	2	3	4	5
G11.	Intelligent	1	2	3	4	5	1	2	3	4	5
G12.	Able to cope	1	2	3	4	5	1	2	3	4	5
G13.	Spiritual or religious	1	2	3	4	5	1	2	3	4	5
G14.	Outgoing	1	2	3	4	5	1	2	3	4	5
G15.	Independent	1	2	3	4	5	1	2	3	4	5
G16.	Realistic	1	2	3	4	5	1	2	3	4	5
G17.	Active	1	2	3	4	5	1	2	3	4	5
G18.	Loved	1	2	3	4	5	1	2	3	4	5
G19.	Caring	1	2	3	4	5	1	2	3	4	5
G20.	Depressed	1	2	3	4	5	1	2	3	4	5

The following questions apply to persons who are <u>married or living</u> with a partner. Please complete them if you are. <u>If you are not married or living with a partner, please skip to Section I on page 13.</u>

Most persons have disagreements in their relationships. Please indicate, with check marks, on the following list, the extent of agreement or disagreement experienced between you and your partner **DURING THE PAST MONTH.** 

		Always Agree	Almost Always Agree	Occa- sionally Disagree	Fre- quently Disagree	Almost Always Disagree	Always Disagree
H1.	Handling family finances					******	
H2.	Matters of recreation						
Н3.	Religious matters						
H4.	Demonstration of affection						
H5.	Friends						
Н6	Sex relations						
H7.	Conventionality (correct or proper behavior						
H8.	Philosophy of life						
Н9.	Ways of dealing with parents or in-laws						
H10.	Aims, goals, and things believed important						
H11.	Amount of time spent together						
H12.	Making major decisions						
H13.	Household tasks						
H14.	Leisure time interests and activities						
H15.	Career decisions						

		All of the time	Most of the time	More often than most	Occa- sionally	Rarely	Never
H16.	How often do you discuss or have you considered divorce, separation, or terminating your relationship?						
H17.	How often do you or your mate leave the house after a fight?						
H18.	In general, how often do you think that things between your and your partner are going well?						
H19.	Do you confide in your mate?						
H20.	Do you ever regret that you married (or lived together)?						
H21.	How often do you and your partner quarrel?						
H22.	How often do you and your mate "get on each other's nerves?"						

		Every Day	Almost Every Day	Occa- sionally	Rarely	Never
H23.	Do you kiss your mate?					
		All of Them	Most of Them	Some of Them	Very few of Them	None of Them
H24.	Do you and your mate engage in outside interests together?					

How often would you say the following events occur between you and your mate?

		Never	Less than once a month	About twice a month	About twice a week	Once a day	More Often
H25.	Have a stimulating exchange of ideas.						
H26.	Laugh together.						
H27.	Calmly discuss something.						
H28.	Work together on a project.						

if eit	ther item	below c	ouples somet aused diffe oast month.	erences of	opinions or	es disagree u were probl	pon. Indicate ems in your
H29.	Being too t	ired for sex	🗆 Y	es 🗆 N	o		
H30.	Not showing	ng love.	□ <b>Y</b>	es 🗆 N	0 .		
H31.	relationsl most rela	nip. The tionships.	middle poi	nt "happy" le the state	represents the nent which b	ne degree of	ess in your happiness of the degree of
		Fairly Inhappy	A Little Unhappy	Happy	Very Happy	Extremely Happy	Perfect
H32.	about the	I want desp see that it of I want very does.  I want very does.  It would be doing now It would be keep the re	perately for my loes.  much for my my my much for my	relationship to relationship to relationship to relationship to relationship to relationship eed. eeded, but I reg. succeed, and	succeed, and we succeed, and we succeed, and we succeed, and we succeeded, but fuse to do any nothere is no more	vould go to almo ill do all I can to ill do my fair sh I can't do much nore than I am d	more than I am loing now to
				SECTION	_1		
	n general, ☐ Excellent		ou say your l y Good	health is: ☐ Good	☐ Fair		or
	Compared now?(Che		ar ago, how	would you	rate your hea	lth in genera	1
] ] ] ]	<ul><li>☐ Somewhat</li><li>☐ About the</li><li>☐ Somewhat</li></ul>	at better nov e same as o	w than one yea	r ago			

13. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much? Please mark the appropriate box to indicate your response.

		YES, limited a lot.	YES, limited a little.	NO, not limited at all.
a.	Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports.			
b.	Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.			
c.	Lifting or carrying groceries.			
d.	Climbing several flights of stairs.			
e.	Climbing one flight of stairs.			
f.	Bending, kneeling, or stooping.			
g.	Walking more than a mile.			
h.	Walking several blocks.			
i.	Walking one block.			
j.	Bathing or dressing yourself.			

I4. **During the past 4 weeks**, have you had any of the following problems with your work or other regular daily activities as a result of your **physical** health?

a.	Cut down the amo	ount of time you spent on work or other activities.
	☐ Yes	□ No
b.	Accomplished less	s than you would like.
	☐ Yes	□ No
c.	Were limited in th	e kind of work or other activities.
	☐ Yes	□ No
d.	Had difficulty per	forming the work or other activities (for example, it took extra effort).
	☐ Yes	□ No

I5.	During the past 4 we other regular daily act anxious)?	v <b>eeks</b> , have ivities as a r	you had an esult of any	ny of the fo	llowing pro problems (su	blems with sch as feelin	your work g depressed	0:
	a. Cut down the amou	ınt of time y	ou spent on	work	☐ Yes		□No	
	or other activities.							
	b. Accomplished less	than you wo	ould like.		☐ Yes	[	□No	
	c. Didn't do work or o	other activiti	es as		☐ Yes		□No	
	carefully as usual.							
I6.	During the past 4 we problems interfered wi groups?	eks, to wha th your norn	t extent has nal social ac	your physic tivities with	al health or family, frien	emotional ds, neighbor	s, or	
	☐ Not at all ☐ Slig	ghtly 🗆 N	Moderately	☐ Quite	a bit $\Box$	Extremely		
I7.	How much bodily pai  ☐ Not at all ☐ Slig		had <b>during</b> Moderately	the past 4		Extremely		
I8.	During the past 4 we work outside the home ☐ Not at all ☐ Slig	and housew	uch did pair ork)? Aoderately	n interfere w ☐ Quite		mal work (i Extremely	ncluding bot	th
19.	These questions a during the past 4 comes closest to the the past 4 weeks:	weeks. It is not be a second to be a	For each on the contract of th	question, p en feeling.	olease give How mu	e the one ch of the t icate your	answer th ime <b>durir</b> response.	ia 1§
	•	All of the time	Most of the time	A good bit of the time	Some of	A little of the time	None of the time	۱
a.	Did you feel full of pep?							
b.	Have you been a very nervous person?							
c.	Have you felt so down in the dumps that nothing could cheer you up?							
d.	Have you felt calm and peaceful?							
e.	Did you have a lot of energy?							
f.	Have you felt downhearted and blue?							

		All of the time	Most of the time	A good bit of the time		A little of the time	None of the time
g.	Have you been a happy person?						
h.	Did you feel tired?						
I10	During the past 4 problems interfered wi	th your sociated the social through the social thro	d activities (  od bit of	the time had like visiting    Some of the time	with friends  f	, relatives, et	or emotiona c.)? one of e time
I11							
		Definitely True	Mosta True	/	on't Know	Mostly False	Definitely False
	seem to get sick a little er than other people.						
	am as healthy as body I know.						
c. I wor	expect my health to get se.						
d. N	Iy health is excellent.						
I12	In the past 6 months, blue, or depressed or in usually liked to do for a. If yes, there was	n which you? fun? □ Y  as such a two	lost all inter	est in things	s like work or	hobbies or t	hings you
	b. If <b>yes</b> , there was psychotherapy? □ yes	•	-week perio	od, did you	get counselin	g or	
	c. If there was su  ☐ yes	ch a two-wee  ☐ no	ek period, di	d you get m	edication for	this condition	n?
I13.	emotional problems?	•	inseling or	psychother	capy or med	ication for o	lepression or

11.	How often do you have a drink containing	g alcohol?			
	□ Never □ Mon	thly or less		Two to four tim	es a month
	☐ Two to three times a week ☐ Fou	r or more ti	mes a weel	•	
J2.	How many drinks containing alcohol do y ☐ 1 or 2 ☐ 3 or 4 ☐ 5 or 6	you have on		ay when you ar 10 or more	e drinking?
J3.	Have you ever felt you should cut down   YES  NO	on your drin	iking?		
J4.	Have people annoyed you by criticizing y ☐ YES ☐ NO	your drinkin	g?		
J5.	Have you ever felt bad or guilty about dr PYES NO				
J6.	Have you ever taken a drink first thir hangover?		orning to s	steady your ne	rves or get rid of
	Listed Below Are Some Symptoms Of Strain Carefully And Check The Answer Which Bed During the Past Three Months.	est Reflects l	e Sometime How Much A little	es Have. Please That Symptom Ouite a bit	: Read Each One Has Bothered You <u>Extremely</u>
	K1. Suddenly scared for no reason				
	K2. Feeling fearful				
	K3. Faintness, dizziness, or weakness				
	K4. Nervousness or shakiness inside				
	K5. Heart pounding or racing				
	K6. Trembling				
	K7. Feeling tense or keyed up				
	K8. Headaches				
	K9. Spells of terror or panic				
	K10. Feeling restless, can't sit still				
	K11. Feeling low in energyslowed down	,			
	K12. Blaming yourself for things				
	K13. Crying easily				

K14. Loss of sexual interest or pleasure							
K15. Poor appetite					_		
K16. Difficult falling asleep, staying asleep							
K17. Feeling hopeless about the future							
K18. Feeling blue							
K19. Feeling lonely							
K20. Feeling trapped or caught							
K21. Worrying too much about things							
K22. Feeling no interest in things							
K23. Thoughts of ending your life							
K24. Feeling everything is an effort							
K25. Feelings of worthlessness							
<ul> <li>Vividly imagine that you are afraid of the the following would you do? Check all of</li> <li>I would ask the dentist exactly what is a tranquilizer or have in the latest to the latest in the latest to the latest in th</li></ul>	a drink be memories when I wo	coing to do. fore going.  ould feel pa	in.	you. the drill.	men of		
I would watch the flow of water from	om my mo	outh to see i	f it contained	blood.			
L2. Vividly imagine that you are being held h Which of the following would you do? Ch  I would sit by myself and have as r	ostage by heck all of	the statem	ents that migh	t apply to you.	uilding.		
I would stay alert and try to keep m				could.			
I would exchange life stories with			cep.		,		
If there was a radio present, I would police were doing.	d stay nea	r it and liste	·		the		
I would watch every movement of	I would watch every movement of my captors and keep an eye on their weapons.						
I would try to sleep as much as pos							
I would think about how nice it's g							
I would make sure I knew where e	I would make sure I knew where every possible exit was.						

L3. Please indicate how much you agree with the following statements.

	T	Strong Disag			S	trongly Agree
a.	If you don't have your health, you don't have anything.	1	2	3	4	5
b.	There are many things I care about more than my health.	1	2	3	4	5
c.	Good health is of only minor importance in a happy life.	1	2	3	4	5
d.	There is nothing more important than good health.	1	2	3	4	5

Please indicate the extent to which each of the following items describes your current family.

	T	Stron Disag	gly	ur curre	S	trongly Agree
M1.	Planning family activities is difficult because we misunderstand each other.	1	2	3	4	5
M2.	In times of crisis we can turn to each other for support.	1	2	3	4	5
М3.	We cannot talk to each other about the sadness we feel.	ot talk to each other about the sadness we 1 2 3		4	5	
M4.	Individuals are accepted for what they are.	1	2	3	4	5
M5.	We avoid discussing our fears and concerns.	1	2	3	4	5
M6.	We can express feelings to each other.	1	2	3	4	5
M7.	There are lots of bad feelings in the family.	1	2	3	4	5
M8.	We feel accepted for what we are.	1	2	3	4	5
M9.	Making decisions is a problem for our family.	1	2	3	4	5
M10.	We are able to make decisions about how to solve problems.	1	2	3	4	5
M11.	We don't get along well together.	1	2	3	4	5
M12.	We confide in each other.	1	2	3	4	5

### THANK YOU VERY MUCH.

CSID [		-	
INTERVI	EWER		

#### Use of SCID modules

#### Depression.

We will be assessing current major depressive episode using the module from the SCID, A1-A5.

(add to A2, item 3: Is that a significant weight loss for you?)

(add to A2, item 4:

Insomnia:

- more than 60 minutes falling asleep

- more than 30 minutes midnight awakening

- more than 60 minutes early morning awakening

Hypersomnia:

- very early to bed

- very late rising

- extended naps (greater than 2 hours)

We then assess past major depressive episode, A12-A18.

We then asses current dysthymia, A38-A43.

#### Substance Use Disorders.

We assess Lifetime Alcohol Abuse/Dependence using the SCID, E1-E7.

#### Anxiety Disorders.

We assess current generalized anxiety disorder, F31-F35.

We then assess current mixed anxiety disorder, J5-J8.

NOTE: Modules for the following pages have not been completed

A-6 through A-11

A-19 through A-37

A-42

F-1 through F-30

J-1 through J-4

			1
1	1	I .	1
1		1	1
1		1	1
1		1	1
1		1 .	1
1		1	ı
1		1	1
1		1	1
l.		4	1
		1	1

# Women's Health Study Telephone Questionnaire Revised 4/19/96

Hello. My name is	I'm calling from the Women's Health Study. Thank you for
returning your questionnai	re. As we had mentioned, we have some questions about your opinions,
experiences, and feelings re	elated to cancer and genetic testing, and about your mood. You may have
provided some of this infor	mation already, but it is important that we update our records. Before we
start, I would like to assure	you that your name was picked randomly from the pool of people that had
volunteered for the genetic	studies. We do not have any new information about your status. I would
<del>-</del>	this interview is confidential and completely voluntary. If we should come to
any questions which you d	o not want to answer or which do not apply to you, just let me know and we
will go on to the next quest	tion. For quality control purposes, we would like to tape record this interview
if that is all right with you.	May we begin?

Length of IW\_\_\_\_\_

Length of Edit\_\_\_\_\_

Interviewer\_

CA	N	CER	ST	A	T	П	S	•
-			U.	_	_	$\mathbf{-}$	~	4

1a. I understand that you (have/have not) been diagnosed with breast cancer.

Breast Cancer Positive
Ovarian Cancer Positive

1. Have Been Diagnosed	5. Have Not

#### IF R INDICATES "HAVE BEEN DIAGNOSED" TO 1a:

1b. When were you diagnosed?

DATE:\_\_\_\_\_(month/year)

1c. On a scale from 1 to 5, with 1 being "not at all distressing" and 5 being "very distressing," how distressed were you by this diagnosis?

Not A Distre			Distr	Very ressing
1	2	3	4	5

2a. I understand that you (have/have not) been diagnosed with ovarian cancer.

1. Have Been	5. Have Not
Diagnosed	

#### IF R INDICATES "HAVE BEEN DIAGNOSED" TO 2a:

2b. When were you diagnosed?

DATE: (month/year)

2c. On a scale from 1 to 5, with 1 being "not at all distressing" and 5 being "very distressing," how distressed were you by this diagnosis?

Not At All Distressing			Distr	Very essing
1	1 2		4	5

#### IF R INDICATES "HAVE BEEN DIAGNOSED" TO EITHER 1a OR 2a OR BOTH:

2d. Have you ever had a second diagnosis of cancer? E.G. AFTER REMISSION, ETC.

1. Yes	5. <b>No</b>

#### IF R INDICATES "YES" TO 2d:

2e. When did you receive this second diagnosis?

$\mathbf{D}$	) /	\T	E:	: '	(month/ye	ar)
_	•				( ) -	,

2f. On a scale from 1 to 5, with 1 being "not at all distressing" and 5 being "very distressing," how distressed were you by this diagnosis?

Not A Distre			Distr	Very essing
1	2	3	4	5

#### IF R INDICATES "YES" or "HAVE BEEN DIAGNOSED" TO 1a, 2a, OR 2d:

2g. Is your cancer currently in remission?

1. Yes	5. <b>No</b>
ł .	ł

#### IF R INDICATES "YES" TO 2g:

2h. How long has your cancer been in remission?

TIME: (mo	onths)
-----------	--------

2i. On a scale from 1 to 5, how distressing is it to be a member of a family that may be at risk for breast cancer?

Not A Distre	-		Distr	Very essing
1 2		3	4	5

A test is now available which allows women in high-risk families to find out if they (personally) have the alteration(s) of a gene (BRCA1) associated with increased risk for breast and ovarian cancer.

2j. On a scale from 1 to 5, how distressing is it to be given the opportunity to be tested for this gene?

Not At All Distressing			Distr	Very essing
1 2		3	4	5

2k. On a scale from 1 to 5, 1 being "not at all," and 5 being "very much," to what extent do you welcome the opportunity to be tested?

Not At All				Very Much
1	2	3	4	5

On a scale from 1 to 5, with 1 being "not at all distressing," and 5 being "very distressing," how distressing would it be to have the test and discover that you have the altered gene that is associated with an increased risk for breast and ovarian cancer?

Not At All			Very	
Distressing			Distressing	
1 2		3	4	5

2m. Using the same scale, how distressing would it be to have the test and discover that you do not have the altered gene?

Not A Distre			Distr	Very essing
1 2		3	4	5

FOR QUESTIONS 3-5b, INDICATE THE NUMBER OF RELATIVES AFFECTED BY CANCER - ENTER ZERO FOR NO CANCER DIAGNOSIS IN A CATEGORY

		Mother	Sister(s)	Daughter(s)	First Aunt(s)	Grandmother(s)	First Cousin(s)
3.	Which of your relatives has had breast cancer?						
4.	Which of your relatives has had ovarian cancer?						
5a.	Have any of your relatives died of breast cancer?						
5b.	Have any of your relatives died of ovarian cancer?						

NOT INCLUDING GREAT-GRANDMOTHERS

RELATIVES	AFFECTED	$\mathbf{RV}$	CANCER.	
KHI A IIVES	Arrea ici	DI	CANCER	

REPEAT THIS SECTION (QUESTIONS 0-10) FOR EACH RELATIVE R INDICATES AFFECTED BY CANCER

\_(years)

	BYC	ANCER							
Now	I am go	ing to asl	k you al	bout yo	ur expe	riences v	with car	ncer among your cl	ose relatives.
Let's	Start w	ith		.=			(relatio	onship)	
0.	Is she	e from yo	ur moth	ner or y	our fath	er's side	of the	family?	
	Mo	ther's	Fath	ier's	]				
		1	2	2					
1.	Whe	n was she	diagno	sed?					
	DAT	E:		_(year)					
	la.	On a so	cale from	m 1 to 5	5, how (	distresse	d were	you by her diagno	sis?
		Not A Distr			Distr	Very essed		Didn't Know IF VOL.	
		1	2	3	4	5		6	
				-					
2.	Is she	e alive?							
		1. Yes	5	. No					
	IF R	ANSWE	RS "NO	<b>)</b> " TO 2	2:				
		2a.			the can	cer or so	methin	g related to it?	
			1. \	Yes	5.	No			
		IF R A	NSWE	RS "YI	ES" To	2a:			
			2b.	When	did she	die?			
				DATE	:		_(year)		
			2c.	How o	old was	she whe	en she d	lied?	
				AGE:_				_(years)	
			2d.	How o	old were	you wh	nen she	died?	

AGE:\_\_\_\_

2e. On a scale from 1 to 5, how distressed were you by this news?

Not A Distr		Very Distressed			
1	2	3	4	5	

Didn't Know IF VOL.	
6	

3. What treatment did she receive? SCORE EACH SURGERY SEPARATELY

Treatment:	1. Yes	5. <b>No</b>
A. Lumpectomy		
B. Unilateral Mastectomy		
C. Bilateral Mastectomy		
D. Oophorectomy (ovaries removed)		
E. Hysterectomy		
F. Chemotherapy		
G. Radiation		
H. Hormonal Therapy	,	
I. Immunotherapy		
J. Don't Know		
K. Other		
L. None		

IF BOTH BREASTS REMOVED IN TWO SEPARATE SURGERIES SCORE YES FOR UNILATERAL AND YES FOR BILATERAL

On a scale of 1 to 5, with 1 being "not at all" and 5 being "very much,"

	Not At All				Very Much	Didn't Know IF VOL.
4. At the time of the illness, how (emotionally) close were you to your (relative)?	1	2	3	4	5	6

On a scale of 1 to 5, with 1 being "not at all" and 5 being "very much",

5. At the time of her illness, how aware were you of the following aspects of your (relative's) condition?

		Not at All		· · · · · · · · · · · · · · · · · · ·		Very Much	Didn't Know If Vol
A.	Diagnosis	1	2	3	4	5	6
B.	Course of illness	1	2	3	4	5	6
C.	Prognosis (what could be expected)	1	2	3	4	5	6
D.	Her pain or suffering	1	2	3	4	5	6
E.	Side effects of treatment	1	2	3	4	5	6
F.	Impairment (not being able to do what she once did) and disruption of her life	1	2	3	4	5	6
G.	How involved were you in the treatment and care of your (relative)?	1	2	3	4	5	6

6. At the time of her illness, did you help care for her in any of the following ways?

	,	1. Yes	5. <b>No</b>
A.	Accompanied to appointments		
B.	Visited at hospital		
C.	Did chores for her		
D.	Provided comfort and emotional support		

On a scale of 1 to 5, with 1 being "not at all" and 5 being "very much,"

		Not At All				Very Much	Didn't Know IF VOL.
7.	At that time, to what extent did you talk with her about her experience?	1	2	3	4	5	6
8.	At that time, how upsetting was her experience with cancer for you? [OVERALL]	1	2	3	4	5	6

		Much More Distant	A Little More Distant	N o Change	A Little Closer	A Lot Closer
9.	At that time, how did your (relative's) illness affect your relationship with other family members? Did it make you[READ OPTIONS]	1	2	3	4	5

On a scale of 1 to 5, with 1 being "not at all" and 5 being "very much,"

		Not At All				Very Much	Didn't Know IF VOL.
10.	How much has your experience with your (relative) affected the way you think about your own risk for cancer and options for dealing with it? [CURRENTLY]	1	2	3	4	5	6

#### REPEAT QUESTIONS 0-10 (STARTING ON PAGE 5) FOR ANY ADDITIONAL RELATIVES

Now I'd like to find out how you keep up with new information about breast cancer (including prevention, detection, and treatment). I'm going to read you a list of sources; On a scale from 1 to 5, with 1 being "not at all" and 5 being "very much," how much do you rely on... REPEAT AS NECESSARY

		Not At All	Very Much			
a.	Your OB/GYN	1	2	3	4	5
b.	Your family physician	1	2	3	4	5
c.	Another physician (Specialty)	1	2	3	4	5
d.	Family Members [WHO GAVE INFO]	1	2	3	4	5
e.	Friends [WHO GAVE INFO]	1	2	3	4	5
f.	Newspapers, television, and radio	1	2	3	4	5
g.	Popular women's magazines	1	2	3	4	5
h.	Other (specify)	1	2	3	4	5

REA	D OPTIONS	Not At All	A Little	Somewhat	A Great Deal
12.	How much do you watch for new information in the media (newspaper, magazines, television, radio)?	1	2	3	4
13.	How much do you try to avoid this information in the media?	1	2	3	4
14.	How much confidence do you have in the accuracy of such information in the media?	1	2	3	4

15bi. Are you aware of the gene (BRCA1) associated with increased risk for early onset breast cancer?

5. No

IF R ANSWERS "YES" TO 15b:	Hopeful	Relieved	Anxious or Fearful	Depressed
15c. Which of the following best describes how you felt when you heard about the discovery of this gene?  READ OPTIONS - R MAY CHOOSE ONLY ONE	1	2	3	4

IF R	ANSWERS "YES" TO 15b:	Not At All	A Little	Somewhat	A Great Deal
15d.	How much did you discuss this development with your mother and/or your sisters? READ OPTIONS	1	2	3	4
15e.	IF R IS MARRIED/PARTNERED: How much have you discussed this development with your (spouse/partner)? READ OPTIONS	1	2	3	4
15f.	IF R HAS CHILDREN: How much have you discussed this development with your children? READ OPTIONS	1	2	3	4

#### 15g. IF R IS CANCER POSITIVE:

Women who are living with breast cancer report various levels of distress. How often do you feel distressed about living with breast cancer?

#### IF R IS CANCER NEGATIVE:

Women who are at risk for breast cancer report various levels of distress. How often do you feel distressed about your risk for breast cancer?

#### **READ OPTIONS**

Never	Rarely	Sometimes	Often
1	2	3	4

15h.	Thinking about your family's risk for breast cancer and your own diagnosis/risk, what has been the mos distressing part?
	disticssing part.

15i. On a scale from 1 to 5, how distressing is this?

Not At All		Very		
Distressing		Distressing		
1	2	3	4	5

#### FOR WOMEN WITH LIVING SISTERS:

SKIP IF R HAS NO LIVING SISTERS

Now I'm going to ask some questions about your relationship with your sisters.

#### 16a. IF R IS CANCER POSITIVE:

How often do you discuss living with breast cancer with your sisters?

#### IF R IS CANCER NEGATIVE:

How often do you discuss your risk for breast cancer with your sisters?

#### **READ OPTIONS**

Never	Rarely	Sometimes	Often
1	2	3	4

IF R ANSWERS "NEVER" TO 16a, DO NOT ASK 16b-d

16b. When you have these discussions, who generally initiates them?

You	Your Sisters	Equally [IF VOLUNTEERED]
1 .	2	3

16c. How satisfied are you with these discussions?

## **READ OPTIONS**

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

16d. What is helpful to you when talking with your sisters about your risk for breast cancer? SCORE ALL THAT APPLY - R CAN CHOOSE MORE THAN ONE - SCORE WHAT IS CURRENTLY HELPFUL, NOT WHAT THEY BELIEVE MIGHT BE HELPFUL

		1. Yes	5. <b>No</b>
1.	Receiving new information.		
2.	The opportunity to express your feelings.		
3.	Receiving comfort or being taken care of.		
4.	Feeling understood.		
5.	Knowing you are not alone.		

16e. Overall, how important is your sister's opinion in your decision whether or not to be tested for the breast cancer gene?

## **READ OPTIONS**

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

In making decisions about what to do to reduce your risk of breast cancer in the future, how important is your sister's opinion?

IF R INSISTS THAT THERE ARE NO MORE DECISIONS TO BE MADE, CODE 1

**READ OPTIONS** 

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

Considering only the positive feelings you have toward your sisters, and ignoring the negative ones, please rate how positive these feelings are. Use a scale of 1 to 10, with 1 being "not at all positive" and 10 being "extremely positive." SCORE GENERAL FEELING TOWARD PERSON, NOT JUST REGARDING CANCER

Not A Posi									remely sitive
1	2	3	4	5	6	7	8	9	10

16h. Considering only the negative feelings you have toward your sisters, and ignoring the positive ones, please rate how negative these feelings are. Use a scale of 1 to 10, with 1 being "not at all negative" and 10 being "extremely negative." SCORE GENERAL FEELING TOWARD PERSON, NOT JUST REGARDING CANCER

	At All ative								remely gative
1	2	3	4	5	6	7	8	9	10

# FOR WOMEN WITH LIVING MOTHERS:

SKIP IF R's MOTHER IS NOT LIVING

Now I am going to ask some questions about your relationship with your mother.

#### 17a. IF R IS CANCER POSITIVE:

How often do you discuss living with breast cancer with your mother?

## IF R IS CANCER NEGATIVE:

How often do you discuss your risk for breast cancer with your mother?

totas, a se como en o en cara en escala cara la como a especial de la como de la como de la como de la como de

#### **READ OPTIONS**

N	lever	Rarely	Sometimes	Often
	1	2	3	4

IF R ANSWERS "NEVER" TO 17a, DO NOT ASK 17b-d

17b. When you have these discussions, who generally initiates them?

You	Your Mother	Equally [IF VOLUNTEERED]
1	2	3

17c. How satisfied are you with these discussions?

# **READ OPTIONS**

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

17d. What is helpful to you when talking with your mother about your risk for breast cancer? SCORE ALL THAT APPLY - R CAN CHOOSE MORE THAN ONE - SCORE WHAT IS CURRENTLY HELPFUL, NOT WHAT THEY BELIEVE MIGHT BE HELPFUL

		1. Yes	5. No
1.	Receiving new information.		
2.	The opportunity to express your feelings.		
3.	Receiving comfort or being taken care of.		
4.	Feeling understood.		
5.	Knowing you are not alone.		

17e. Overall, how important is your mother's opinion in your decision whether or not to be tested for the breast cancer gene?

**READ OPTIONS** 

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

17f. In making decisions about what to do to reduce your risk of breast cancer in the future, how important is your mother's opinion?
IF R INSISTS THAT THERE ARE NO MORE DECISIONS TO BE MADE, CODE 1

**READ OPTIONS** 

Not At All	A Little	Somewhat	A Great Deal	
1	2.	3	4	

Considering only the positive feelings you have toward your mother, and ignoring the negative ones, please rate how positive these feelings are. Use a scale of 1 to 10, with 1 being "not at all positive" and 10 being "extremely positive." SCORE GENERAL FEELING TOWARD PERSON, NOT JUST REGARDING CANCER

Not A Posi									remely sitive
1	2	3	4	5	6	7	8	9	10

17h. Considering only the negative feelings you have toward your mother, and ignoring the positive ones, please rate how negative these feelings are. Use a scale of 1 to 10, with 1 being "not at all negative" and 10 being "extremely negative." SCORE GENERAL FEELING TOWARD PERSON, NOT JUST REGARDING CANCER

Not A Nega									remely gative
1	2	3	4	5	6	7	8	9	10

# FOR WOMEN WHO ARE MARRIED OR LIVING WITH A PARTNER: SKIP IF R IS NOT MARRIED/PARTNERED

Now I am going to ask you some questions about your relationship with your (husband/partner).

# 18a. IF R IS CANCER POSITIVE:

How often do you discuss living with breast cancer with your husband/partner?

# IF R IS CANCER NEGATIVE:

How often do you discuss your risk for breast cancer with your husband/partner?

#### **READ OPTIONS**

Never	Rarely	Sometimes	Often	
1	2	3	4	

IF R ANSWERS "NEVER" TO 18a, DO NOT ASK 18b-d

18b. When you have these discussions, who generally initiates them?

You	Your Husband/ Partner	Equally [IF VOLUNTEERED]	
1	2	3	

18c. How satisfied are you with these discussions?

# **READ OPTIONS**

Not At All	A Little	Somewhat	A Great Deal	
1	2	3	4	

18d. What is helpful to you when talking with your husband/partner about your risk for breast cancer? SCORE ALL THAT APPLY - R CAN CHOOSE MORE THAN ONE - SCORE WHAT IS CURRENTLY HELPFUL, NOT WHAT THEY BELIEVE MIGHT BE HELPFUL

		1. Yes	5. <b>No</b>
1.	Receiving new information.		
2.	The opportunity to express your feelings.		
3.	Receiving comfort or being taken care of.		
4.	Feeling understood.		
5.	Knowing you are not alone.		

18e. Overall, how important is your husband/partner's opinion in your decision whether or not to be tested for the breast cancer gene?

#### **READ OPTIONS**

Not At All	A Little	Somewhat	A Great Deal	
1	2	3	4	

In making decisions about what to do to reduce your risk of breast cancer in the future, how important is your (husband's/partner's) opinion?

IF R INSISTS THAT THERE ARE NO MORE DECISIONS TO BE MADE, CODE 1

RE.	AD	OP	T	ON	2
	1	$\mathbf{v}$		U.	

Not At All	Not At All A Little		A Great Deal	
1	2	3	4	

Considering only the positive feelings you have toward your husband/partner, and ignoring the negative ones, please rate how positive these feelings are. Use a scale of 1 to 10, with 1 being "not at all positive" and 10 being "extremely positive." SCORE GENERAL FEELING TOWARD PERSON, NOT JUST REGARDING CANCER

Not A Posi									remely sitive
1	2	3	4	5	6	7	8	9	10

18h. Considering only the negative feelings you have toward your husband/partner, and ignoring the positive ones, please rate how negative these feelings are. Use a scale of 1 to 10, with 1 being "not at all negative" and 10 being "extremely negative." SCORE GENERAL FEELING TOWARD PERSON, NOT JUST REGARDING CANCER

Not A Nega									remely gative
1	2	3	4	5	6	7	8	9	10

# FOR WOMEN WITH LIVING DAUGHTER/S: SKIP IF R HAS NO LIVING DAUGHTER/S

Now I am going to ask you some questions about your relationship with your daughter/s.

19i.	What are the ages of your daughters?							

19ii. In general, do you discuss family history and risk for breast cancer with your daughter/s?

19e. Overall, how important is/are your daughters' opinion in your decision whether or not to be tested for the breast cancer gene?

#### **READ OPTIONS**

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

In making decisions about what to do to reduce your risk of breast cancer in the future, how important is/are your daughter's opinion/s?

IF R INSISTS THAT THERE ARE NO MORE DECISIONS TO BE MADE, CODE 1

#### **READ OPTIONS**

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

19g. Considering only the positive feelings you have toward your daughters, and ignoring the negative ones, please rate how positive these feelings are. Use a scale of 1 to 10, with 1 being "not at all positive" and 10 being "extremely positive." SCORE GENERAL FEELING TOWARD PERSON, NOT JUST REGARDING CANCER

Not A Posi									emely sitive
1	2	3	4	5	6	7	8	9	10

19h. Considering only the negative feelings you have toward your daughters, and ignoring the positive ones, please rate how negative these feelings are. Use a scale of 1 to 10, with 1 being "not at all negative" and 10 being "extremely negative." SCORE GENERAL FEELING TOWARD PERSON, NOT JUST REGARDING CANCER

	Not At All Extren Negative Negat								
1	2	3	4	5	6	7	8	9	10

# FOR WOMEN WITH CHILDREN:

SKIP IF R HAS NO CHILDREN

19iii. If you should choose to obtain genetic testing, do you intend to inform your children of the results?

1. Yes 5. No	7. <b>Undecided</b> [IF VOLUNTEERED]
--------------	--------------------------------------

FOR .	AT.	T. 1	VΩ	MEN	J:
ruk .	/A L .	1 1	YY 🗤	TVI ET	٧.

20.		were to find that you were a carrier for BRCA1, the gene for increased risk of breast cancer, what as would you consider?						
•								
IDON	El							

CSID	-
INTERVIEWER	

# Use of SCID modules

# Depression.

We will be assessing current major depressive episode using the module from the SCID, A1-A5.

(add to A2, item 3: Is that a significant weight loss for you?)

(add to A2, item 4:

Insomnia:

- more than 60 minutes falling asleep

- more than 30 minutes midnight awakening

- more than 60 minutes early morning awakening

Hypersomnia:

- very early to bed

- very late rising

- extended naps (greater than 2 hours)

We then assess past major depressive episode, A12-A18.

We then asses current dysthymia, A38-A43.

# Substance Use Disorders.

We assess Lifetime Alcohol Abuse/Dependence using the SCID, E1-E7.

# Anxiety Disorders.

We assess current generalized anxiety disorder, F31-F35.

We then assess current mixed anxiety disorder, J5-J8.

IN THIS SECTION, MAJOR DEPRESSIVE, MANIC HYPOMANIC EPISODES, DYSTHYMIC DISORDER, MOOD DISORDER DUE TO A GENERAL MEDICAL CONDITION, SUBSTANCE-INDUCED MOOD DISORDER, AND EPISODE SPECIFIERS ARE EVALUATED. MAJOR DEPRESSIVE DISORDER AND BIPOLAR DISORDERS ARE DIAGNOSED IN MODULE D.

## CURRENT MAJOR DEPRESSIVE EPISODE

Now I am going to ask you some more questions about your mood.

In the last month...

...has there been a period of time when you were feeling depressed or down most of the day nearly every day? (What was that like?)

IF YES: How long did it last? (As long as two weeks?) When did it begin?

...what about having little interest or pleasure in doing things?

IF YES: Was it nearly every day? How long did it last? (As long as two weeks?)

#### **MDE CRITERIA**

A. Five (or more) of the following symptoms have been present during the same two week period and represent a change from previous functioning; at least one of the symptoms is either (1) depressed mood or (2) loss of interest or pleasure.

- (1) depressed mood most of the day, nearly every day, as indicated either by subjective report (e.g., feels sad or empty) or observation made by others (e.g., appears tearful). Note: in children and adolescents, can be irritable mood.
- (2) markedly diminished interest or pleasure in all, or almost all, activities most of the day, nearly every day (as indicated either by subjective account of observation made by others)

NOTE: WHEN RATING THE FOLLOWING ITEMS, CODE "1" IF CLEARLY DUE TO A GENERAL MEDICAL CONDITION, MOOD-INCONGRUENT DELUSIONS OR HALLUCINATIONS ? 1 2 3 A1

? 1 2 3 A2

IF NEITHER ITEM (1) NOR ITEM (2) IS CODED "3," GO TO \*PAST MAJOR DEPRESSIVE EPISODE\*, A.12

# FOR THE FOLLOWING QUESTIONS, FOCUS ON THE WORST TWO WEEKS IN THE PAST MONTH (OR ELSE THE PAST TWO WEEKS IF EQUALLY DEPRESSED FOR THE ENTIRE MONTH

During this (TWO WEEK PERIOD)...

rekiod)						
did you lose or gain any weight? (How much?) (Were you trying to lose weight?)  IF NO: How was your appetite? (What about compared to your usual appetite?) (Did you have to force yourself to eat?) (Eat [less/more] than usual?) (Was that nearly every day?)	(3) significant weight loss when not dieting, or weight gain (e.g., a change of more than 5% of body weight in a month) or decrease or increase in appetite nearly every day. Note: in children, consider failure to make expected weight gains.  Check if: weight loss or decreased appetiteweight gain or increased appetite	?	1	2	3	A4 A5
how were you sleeping? (Trouble falling asleep, waking frequently, trouble staying asleep, waking too early, OR sleeping too much? How many hours a night compared to usual?	(4) insomnia or hypersomnia nearly every day  Check if:insomnia	?	1	2	3	A6
Was that nearly every night?)	hypersomnia					A8
were you so fidgety or restless that you were unable to sit still? (Was it so bad that other people noticed it? What did they notice? Was that nearly every day?)	(5) psychomotor agitation or retardation nearly every day (observable by others, not merely subjective feelings of restlessness or being slowed down)	?	1	2	3	А9
IF NO: What about the opposite talking or moving more slowly than is normal for you? (Was it so bad that other people noticed it? What	NOTE: CONSIDER BEHAVIOR DURING THE INTERVIEW Check if:psychomotor retardationpsychomotor agitation					A10 A11
did they notice? Was that nearly every day?) what was your energy like? (Tired all the time? Nearly every day?)	(6) fatigue or loss of energy nearly every day	?	1	2	3	A12
? = inadequate information	1 = absent or false 2 = subthresho	old	3 =thr	eshold (	or true	

SCID (DSM-IV)	Current MDE (WHS 3/96)	Mood Episo	des		A.3
During this time how did you feel about yourself? (Worthless?) (Nearly every day?)  IF NO: What about feeling guilty about things you had done or not done? (Nearly every day?)	(7) feelings of worthlessness or excessive or inappropriate guilt (which may be delusional) nearly every day (not merely self-reproach or guilt about being sick)  NOTE: CODE "1" OR "2" IF ONLY LOW SELF-ESTEEM check if:	? 1	2	3	A13
	worthlessinappropriate guilt				A14 A15
did you have trouble thinking or concentrating? (What kinds of things did it interfere with?) (Nearly every day?)  IF NO: Was it hard to make	(8) diminished ability to think or concentrate, or indecisiveness, nearly every day (either by subjective account or as observed by others)	? 1	2	3	A16
decisions about everyday things? (Nearly every day?)	check if:diminished ability to thinkindecisiveness				A17 A18
were things so bad that you were thinking a lot about death or that you would be better off dead? What about thinking of hurting yourself?  IF YES: Did you do anything to hurt yourself?	(9) recurrent thoughts of death (not just fear of dying), recurrent suicidal ideation without a specific plan, or a suicide attempt or a specific plan for committing suicide	? 1	2	3	A19
00 IIII 9 0 II 00 1	NOTE: CODE "1" FOR SELF- MUTILATION W/O SUICIDAL INTENT				
	Check if:thoughts of own deathsuicidal ideationspecific plansuicide attempt				A20 A21 A22 A23
	AT LEAST FIVE OF THE ABOVE SXS [A (1-9)]ARE CODED "3" AND AT LEAST ONE OF THESE IS ITEM (1) OR (2)  IF UNCLEAR, GO TO PAGE A.1	GO TO *PAST MAJOR DEPRES- SIVE EPI- SODE*, A.12		3	A24

IF UNCLEAR: Has (depressive episode/OWN EQUIVALENT) made it hard for you to do your work, take care of things at home, or get along with other people?

B. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.

? 1 2 3 A25

GO TO \*PAST

MAJOR DE
PRESSIVE

EPISODE\*

A.12

Just before this began, were you physically ill?

Just before this began, were you taking any medications?

IF YES: Any change in the amount you were taking?

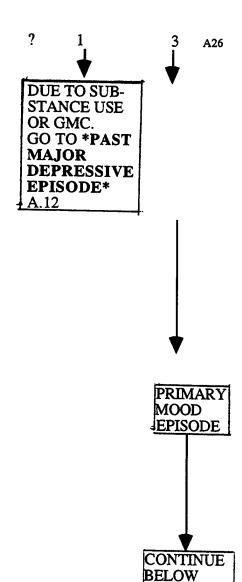
Just before this began, were you drinking or taking any street drugs?

C. Not due to the direct physiological effects of a substance (e.g., a drug of abuse, medication) or to a general medical condition

IF GENERAL MEDICAL
CONDITION OR
SUBSTANCE MAY BE
ETIOLOGICALLY
ASSOCIATED WITH
DEPRESSION, GO TO
\*GMC/SUBSTANCE\*
A.43 AND RETURN HERE
TO MAKE RATING OF "1" OR
"3."

Etiological general medical conditions include: degenerative neurological illnesses (e.g., Parkinson's disease,
Parkinson's disease,
Huntington's disease,
cerebrovascular disease,
metabolic and endocrine
conditions [e.g., B-12
deficiency, hypothyroidism],
autoimmune conditions [e.g.,
systemic lupus erythematosus],
viral or other infections [e.g.,
hepatitis, mononucleosis, HIV],
and certain cancers [e.g.,
carcinoma of the pancreas]

Etiological substances include alcohol, amphetamines, cocaine, hallucinogens, inhalants, opioids, phencyclidine, sedatives, hypnotics, anxiolytics, and other or unknown substances (e.g., steroids)



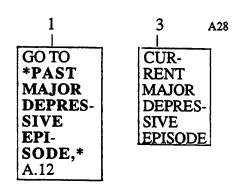
A29

(Did this begin soon after someone close to you died?)

D. Not better accounted for by Bereavement, i.e., after the loss of a loved one, the symptoms persist for longer than 2 months or are characterized by marked functional impairment, morbid preoccupation with worthlessness, suicidal ideation, psychotic symptoms, or psychomotor retardation.

3 1 A27 SIMPLE NOT SIM-BEREAVE-PLE **MENT** BEREAVE-MENT GO TO \*PAST CONTINUE **MAJOR BELOW DEPRES-**SIVE EPI-SODE\* A.12

MAJOR DEPRESSIVE EPISODE CRITERIA A, B, C and D are coded "3"



How many separate times have you been (depressed/OWN EQUIVALENT) nearly every day for at least two weeks and had several of the symptoms that you described, like (SXS OF WORST EPISODE)?

How old were you when (CURRENT MAJOR DEPRESSIVE EPISODE) started?

Total number of Major Depressive Episodes, including current (CODE 99 IF TOO NUMEROUS OR INDISTINCT TO COUNT)

Age at onset of Current Major Depressive Episode

Mo/Yr: \_\_\_\_/ \_\_\_ Age:\_\_\_\_

IF UNCLEAR, ESTABLISH WHETHER MDE OR CANCER DX. CAME FIRST. CODE THIS INFORMATION ON SUMMARY SCORE SHEET.

# \*PAST MAJOR DEPRESSIVE EPISODE\*

- -> IF NOT CURRENTLY
  DEPRESSED: Have you
  ever had a period when you
  were feeling depressed or
  down most of the day nearly
  every day? (What was that
  like?)
- I-> IF CURRENTLY
  DEPRESSED OR DOES
  NOT MEET FULL
  CRITERIA FOR PAST
  MDE: Has there been
  another time when you were
  depressed or down most of
  the day nearly every day?
  (What was that like?)

IF YES: When was that? How long did it last? (As long as two weeks?)

- -> IF PAST DEPRESSED
  MOOD: During that time,
  did you have little interest or
  pleasure in doing things you
  usually enjoyed? (What was
  that like?)
- I-> IF NO PAST DEPRESSED MOOD: What about a time when you had little interest or pleasure in doing things you usually enjoyed? (What was that like?)

IF YES: When was that? Was it nearly every day? How long did it last? (As long as two weeks?)

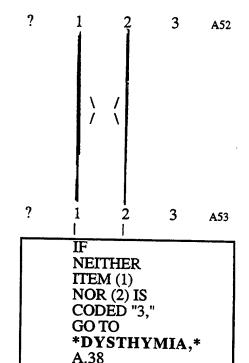
Have you had more than one time like that? (Which time was the worst?)

IF UNCLEAR: Have you had any times like that in the past year?

# **MDE CRITERIA**

A. Five or more of the following symptoms have been present during the same two week period and represent a change from previous functioning; at least one of the symptoms was either (1) depressed mood or (2) loss of interest or pleasure.

- (1) depressed mood most of the day, nearly every day, as indicated by either subjective report (e.g., feels sad or empty) or observation made by others (e.g., appears tearful). Note: in children and adolescents, can be irritable mood.
- 2) markedly diminished interest or pleasure in all, or almost all, activities most of the day, nearly every day (as indicated either by subjective account or observation made by others)



NOTE: IF MORE THAN ONE PAST EPISODE IS LIKELY, SELECT THE "WORST" ONE FOR YOUR INQUIRY ABOUT A PAST MAJOR DEPRESSIVE EPISODE. HOWEVER, IF THERE WAS AN EPISODE IN THE PAST YEAR, ASK ABOUT THAT EPISODE EVEN IF IT WAS NOT THE WORST.

SCID-I (DSM-IV) Version 2.0	Past MDE	(WHS 3/96)	Mo	od Epis	odes		A.13
FOR THE FOLLOWING QUESTIONS, FOCUS ON THE WORST TWO WEEKS OF THE PAST MDE YOU ARE EVALUATING. DO NOT EVALUATE A CURRENT MDE.  During that (TWO WEEK PERIOD)	FOLLOW "1" IF CL DUE TO A MEDICA TO MOO DELUSIO	VHEN RATING THE YING ITEMS, CODE EARLY DIRECTLY A GENERAL L CONDITION, OR D-INCONGRUENT DNS OR INATIONS					
did you lose or gain any weight? (How much?) (Were you trying to lose weight?)  IF NO: How was your appetite? (What about compared to your usual appetite?) (Did you have to force yourself to eat?) (Eat	not dieting a change of body weig decrease of nearly even children, of	icant weight loss when g, or weight gain (e.g., of more than 5% of this in a month) or increase in appetite cry day. Note: in consider failure to exted weight gains.	?	1	2	3	A54
[less/more] than usual?) (Was that nearly every day?)	ap w	reight loss or decreased opetite reight gain or increased opetite					A55 A56
how were you sleeping? (Trouble falling asleep, waking frequently, trouble staying asleep, waking too early, OR	(4) insom nearly eve Check if:	nia or hypersomnia ry day	?	1	2	3	A57
sleeping too much? How many hours a night compared to usual? Was that nearly every night?)		_ insomnia hypersomnia					A58 A59
were you so fidgety or restless that you were unable to sit still? (Was it so bad that other people noticed it? What did they notice? Was that nearly every day?)	retardation (observabl merely sub	omotor agitation or nearly every day le by others, not ojective feelings of ss or being slowed	?	1	2	3	A60
IF NO: What about the opposite talking or moving more slowly than is normal for you? (Was it so bad that other people noticed it? What did they notice? Was that nearly every day?)		osychomotor retardation osychomotor agitation					A61 A62
what was your energy like? (Tired all the time? Nearly every day?)		e or loss of urly every day	?	1	2	3	A63

SCID-I (DSM-IV) Version 2.0	Past MDE	(WHS 3/96)	Mood E	pisodes		A.	14
how did you feel about yourself? (Worthless?) (Nearly every day?)  IF NO: What about feeling guilty about things you had done or not done? (Nearly every day?)	excessive or (which may every day (1 or guilt about the control of	s of worthlessness or r inappropriate guilt be delusional) nearly not merely self-reproach ut being sick)  DDE "1" OR "2" IF W SELF-ESTEEM  orthless appropriate guilt	?	1	2	3	A64 A65 A66
did you have trouble thinking or concentrating? (What kinds of things did it interfere with?) (Nearly every day?)  IF NO: Was it hard to make decisions about everyday things? (Nearly every day?)	concentrate, nearly every subjective a by others)  check if:dimin	hed ability to think or , or indecisiveness, , day (either by ccount or as observed ished ability to think cisiveness	?	1	2	3	A67 A68 A69
were things so bad that you were thinking a lot about death or that you would be better off dead? What about thinking of hurting yourself?  IF YES: Did you do anything to hurt yourself?	(not just fea suicidal idea plan, or a su specific plan NOTE: CO	nt thoughts of death r of dying), recurrent ation without a specific icide attempt or a n for committing suicide DE "1" FOR SELF- ON W/O SUICIDAL	?	1	2	3	A70
		ughts of own death cidal ideation ecific plan cide attempt					A71 A72 A73 A74

SCID-I (DSM-IV) Version 2.0	Past MDE (WHS 3/96)	Mood Episodes		A.15	5
	AT LEAST FIVE OF TH ABOVE SXS [A(1-9)] A CODED "3" AND AT LE ONE OF THESE IS ITE OR (2)	RE EAST	1	3	A75
IF NOT ALREADY ASKED: Has there ever been any other time when you were (depressed/own equivalent) and had even more of the symptoms than I just asked you about?			J		
-> IF YES: RETURN TO *PAST MAJOR DEPRESSIVE EPISODE* A.12 AND CHECK WHETHER THERE HAVE BEEN ANY OTHER MAJOR DEPRESSIVE EPISODES THAT WERE MORE SEVERE AND/OR CAUSED MORE SYMPTOMS. IF SO, ASK ABOUT THAT EPISODE.					
> IF NO: GO TO *CURRENT DYSTHYMIA* A.38					
IF UNCLEAR: Has (depressive episode/own equivalent) made it hard for you to do your work, take care of things at home, or get along with other people?	B. The symptoms cause clinically significant distrimpairment in social, occupational, or other impareas of functioning.		1		3a76 I CON- TINUE
IF NOT ALREADY ASKED:			<u> </u>		

IF NOT ALREADY ASKED: Has there been any other time when you were (depressed/ OWN EQUIVALENT) and it caused you even more problems than I just asked you about?

> IF YES: RETURN TO \*PAST MAJOR DEPRESSIVE EPISODE\* A.12 AND CHECK WHETHER THERE HAVE BEEN ANY OTHER MAJOR DEPRESSIVE EPISODES THAT WERE MORE SEVERE AND/OR CAUSED MORE SYMPTOMS. IF SO, ASK ABOUT THAT EPISODE.

l-> IF NOT: GO TO \*CURRENT DYSTHYMIA\* A.38

? = inadequate information

1 = absent or false

2 =subthreshold

3 =threshold or true

# SCID-I (DSM-IV) Version 2.0

Just before this began, were you physically ill?

IF YES: What did the doctor say?

Just before this began, were you taking any medications?

IF YES: Any change in the amount you were taking? Did you begin a new medication?

Just before this began, were you drinking or taking any street drugs?

Past MDE (WHS 3/96)

Mood Episodes

A.16

A77

C. Not due to the direct physiological effects of a substance (e.g., a drug of abuse, medication) or to a general medical condition

DUE TO SUB-STANCE USE OR GMC

1

IF GENERAL MEDICAL
CONDITION OR SUBSTANCE
MAY BE ETIOLOGICALLY
ASSOCIATED WITH
DEPRESSION, GO TO
\*SUBSTANCE/GMC\* A.43.
AND RETURN HERE TO MAKE
RATING OF "1" OR "3."

REFER TO LIST OF GENERAL MEDICAL CONDITIONS AND SUBSTANCES, A.4.

IF UNKNOWN: Has there been any other time when you were depressed like this but were not using SUBSTANCE/ ill with GMC)?

> IF YES; GO TO \*PAST
MAJOR DEPRESSIVE
EPISODE\* A.12 AND
CHECK WHETHER THERE
HAVE BEEN ANY OTHER
MAJOR DEPRESSIVE
EPISODES THAT WERE
MORE SEVERE AND/OR
CAUSED MORE
SYMPTOMS. IF SO, ASK
ABOUT THAT EPISODE.

L> IF NO: GO TO \*CURRENT DYSTHYMIA\* A.38

PRIMARY MOOD EPISODE

CONTINUE

SCID-I (DSM-IV) Version 2.0	Past MDE (WHS 3/96)	Mood Episodes	A.17
(Did this begin soon after someone close to you died?)	D. Not better accounted for by Bereavement, i.e., after the loss of a loved one, the symptoms persist for longer than 2 months or are characterized by marked functional impairment, morbid preoccupation with worthlessness, suicidal ideation, psychotic symptoms, or psychomotor retardation.	SIMPLE BEREAVE- MENT	AT LEAST ONE MAJOR EPISODE NOT SIMPLE BEREAVE- MENT
IF UNKNOWN: Has there been any other time when you were depressed like this that did not occur after someone close to you died?			
-> IF YES: GO TO *PAST MAJOR DEPRESSIVE EPISODE* A12 AND CHECK WHETHER THERE HAVE BEEN ANY OTHER MAJOR DEPRESSIVE EPISODES THAT WERE MORE SEVERE AND/OR CAUSED MORE SYMPTOMS. IF SO, ASK ABOUT THAT EPISODE.		•	
-> IF NO: GO TO *CURRENT			CON- TINUE
DYSTHYMIA* A.38	MAJOR DEPRESSIVE EPISODE CRITERIA A, B, C and D are coded "3"	GO TO *CUR- RENT DYSTHY- MIA*	3 A79 PAST MAJOR DEPRES- SIVE EPISODE
How old were you when (PAST MAJOR DEPRESSIVE EPISODE) started?	Age at onset of Past Major Depressive Episode (coded above)		A80
How many separate times have you been (depressed/OWN EQUIVALENT) nearly every day for at least two weeks and had several of the symptoms that you described, like (SXS OF WORST EPISODE)?	Total number of Major Depressive Episodes, including current (CODE 99 IF TOO NUMEROUS OR INDISTINCT TO COUNT)		A81

<sup>? =</sup> inadequate information

SCID-I (DSM-IV) Version 2.0

Past MDE (WHS 3/96)

Mood Episodes

A.18

IF UNKNOWN: How old were you when first started having (SXS OF MDE)?

Age of onset of first Major Depressive Episode (CODE 99 IF UNKNOWN)

Mo./Yr.:\_\_\_/\_\_ Age:\_\_\_

ESTABLISH WHETHER MDE OR CANCER DX. CAME FIRST. CODE THIS INFORMATION ON SUMMARY SCORE SHEET.

# \*DYSTHYMIC DISORDER\* (CURRENT ONLY)

r> IF NO MAJOR DEPRESSIVE EPISODE IN THE PAST TWO YEARS: For the past couple of years, have you been bothered by depressed mood most of the day, more days than not? (More than half the time?)

IF YES: What was that like?

-> IF CURRENT MAJOR DEPRESSIVE EPISODE: Let's review when you first had most of the symptoms of (CURRENT MAJOR DEPRESSIVE EPISODE). For the two years prior to (BEGINNING DATE). were you bothered by depressed moods, most of the day, more days than not? (More than half the time?)

> FOR A PAST MAJOR DEPRESSIVE EPISODE **DURING THE PAST TWO** YEARS: Let's review when you first had most of the symptoms of FIRST MET CRITERIA FOR (PAST MAJOR DEPRESSIVE EPISODE) and the point at which you no longer had most of the symptoms. Since the (DATE OF NO LONGER MEETING CRITERIA), have you still been bothered by depressed mood, so that you have been depressed for most of the day, more days than not?

IF YES: For the two years prior to (DATE OF BEGINNING OF PAST MAJOR DEPRESSIVE EPISODE), were you bothered by depressed mood, most of the day. more days than not? (More than half the time?)

# DYSTHYMIC DISORDER CRITERIA

A. Depressed mood (or can be irritable mood in children and adolescents) for most of the day. for more days than not, as indicated either by subjective account or observation made by others, for at least two years (one year for children and adolescents)

?	1	2	3	A163
	GO TO *ALCO USE			
	E.1	RDERS*		

FIRST MET CRITERIA FOR CURRENT MAJOR DEPRESSIVE EPISODE (see A.5):

Mo/Yr: \_\_\_\_/ \_\_ Age:

PAST MAJOR DEPRESSIVE EPISODE (see A.17):

Mo/Yr: \_\_\_\_\_/ \_\_\_ Age: \_\_\_\_

NO LONGER MET CRITERIA FOR PAST MAJOR DEPRESSIVE EPISODE IN PAST TWO YEARS: Mo/Yr: \_\_\_\_/ \_\_\_ Age: \_\_\_\_

SCID-I (DSM-IV)	ysthymic Disorder	(WHS 3/96)	Mood	Episode	es		A .39
During these periods of (OWN EQUIVALENT FOR CHRONIC DEPRESSION), do you often	two (or more	e, while depressed, of e) of the following:					
lose you appetite?(What about overeating?)	(1) poor app	etite or overeating	?	1	2	3	A164
have trouble sleeping or sleep too much	(2) insomnia	or hypersomnia	?	1	2	3	A165
have little energy to do things feel tired a lot?	or (3) low ener	gy or fatigue	?	1	2	3	A166
feel down on yourself? (Feel worthless, or a failure?)	(4) low self-e	esteem	?	1	2	3	A167
have trouble concentrating or making decisions?	(5) poor con making decis	centration or difficulty	?	1	2	3	A168
feel hopeless?	(6) feelings	of hopelessness	?	1	2	3	A169
	AT LEAST T SYMPTOMS	TWO "B" S CODED "3"	*/	1 O TO ALCOH SE DI RDER 1	S-	3	A170
What is the longest period of tim during this period of long-lasting depression, that you felt ok?(NO DYSTHYMIC SYMPTOMS)	(one-year for adolescents) of person has nest symptoms in than two more NOTE: COD	of the disturbance, the ever been without the A and B for more of this at a time.  DE "1" IF NORMAL AT LEAST TWO	*/ U	1 O TO ALCOH SE DI RDER	S-	3	A171

A172

3

How long have you been feeling this way? (When did this begin?)

COMPARE ONSET OF DYSTHYMIC SXS WITH DATES OF PAST MAJOR DEPRESSIVE EPISODES TO DETERMINE IF THERE WERE ANY MAJOR DEPRESSIVE EPISODES IN FIRST TWO YEARS OF DYSTHYMIC DISORDER. D. No major depressive episode during the first two years of disturbance (one year for children and adolescents); i.e., not better accounted for by chronic Major Depressive Disorder in partial remission.

GO TO
\*ALCOHOL
USE DISORDERS\*
E.1

Age at onset of current Dysthymic Disorder (CODE 99 IF UNKNOWN)

A173

IF MAJOR DEPRESSIVE
EPISODE PRECEDED
DYSTHYMIC SXS: Now I want
to know whether you got
completely back to your usual self
after that (MAJOR DEPRESSIVE
EPISODE) you had (DATE),
before this long period of being
mildly depressed? (Were you back
to your usual self for at least two
months?)

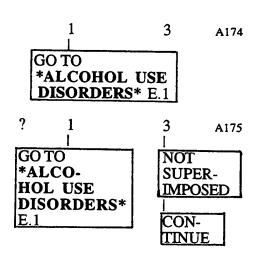
Note: There may have been a previous Major Depressive Episode provided there was a full remission (no significant signs or symptoms for two months) before development of the Dysthymic Disorder. In addition, there may be superimposed episodes of Major Depressive Disorder, in which case both diagnoses may be given.

NOTE: CODE "3" IF NO PAST MAJOR DEPRESSIVE EPISODES OR IF MAJOR DEPRESSIVE EPISODES WERE NOT PRESENT DURING THE FIRST TWO YEARS OR IF THERE WAS AT LEAST A TWO MONTHS PERIOD WITHOUT SYMPTOMS PRECEDING THE ONSET.

E. Has never had a Manic Episode or an unequivocal Hypomanic Episode.

F. Does not occur exclusively during the course of a chronic psychotic disorder, such as Schizophrenia or Delusional Disorder.

NOTE: CODE "3" IF NO CHRONIC PSYCHOTIC DISORDER OR IF NOT SUPERIMPOSED ON A CHRONIC PSYCHOTIC DISORDER.



IF DYSTHYMIC DISORDER Indicate specifier:

1- Early Onset: onset before age 21 2- Late Onset: onset age 21 or older Specifier: \_\_\_\_

A179

<sup>? =</sup> inadequate information

?

# \*GMC/SUBSTANCE CAUSING MOOD/ANXIETY SYMPTOMS\*

MOOD/ANXIETY DISORDER DUE TO A GENERAL MEDICAL CONDITION MOOD/ANXIETY DISORDER DUE TO A GENERAL MEDICAL CRITERIA

IF SYMPTOMS NOT TEMPORALLY ASSOCIATED WITH A GENERAL MEDICAL CONDITION, CHECK HERE\_\_\_\_ AND GO TO \*SUBSTANCE INDUCED MOOD DISORDER\*, A45.

A187

A188

A190

CODE BASED ON INFORMATION ALREADY OBTAINED.

A. Prominent and persistent disturbance in mood/anxiety characterized by the following:

- (1) depressed mood or markedly diminished interest or pleasure in all, or almost all, activities [FOR MOOD]
- (2) prominent anxiety, panic attacks, obsession or compulsions [FOR ANXIETY]

? 1 3 A189

2

3

3

Do you think your (MOOD/ ANXIETY SXS) were in any way related to your (COMORBID GENERAL MEDICAL CONDITION)?

IF YES: Tell me how.

(Did the [MOOD/ANXIETY SXS] start or get much worse only after [COMORBID GENERAL MEDICAL CONDITION] began?)

IF YES AND GMC HAS RESOLVED: Did the (MOOD/ANXIETY SXS) get better once the (COMORBID GENERAL MEDICAL CONDITION) got better? B./C. There is evidence from the history, physical examination, or laboratory findings that the disturbance is the direct physiological consequence of a general medical condition and the disturbance is not better accounted for by another mental disorder (e.g., Adjustment Disorder With Depressed Mood, in response to the stress of having a general medical condition).

THE FOLLOWING FACTORS SHOULD BE CONSIDERED AND SUPPORT THE CONCLUSION THAT THE GMC IS ETIOLOGIC TO THE MOOD/ANXIETY SXS:

- 1) THERE IS EVIDENCE FROM THE LITERATURE OF A WELL-ESTABLISHED ASSOCIATION BETWEEN THE GMC AND MOOD/ANXIETY SYMPTOMS.
- 2) THERE IS A CLOSE TEMPORAL RELATIONSHIP BETWEEN THE COURSE OF THE MOOD/ANXIETY SXS AND THE COURSE OF THE GENERAL MEDICAL CONDI-TION.

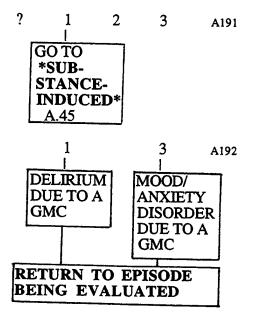
? 1 2
GO TO
\*SUBSTANCE
INDUCED\*
A.45

1

- 3) THE MOOD/ANXIETY SYMP-TOMS ARE CHARACTERIZED BY UNUSUAL PRESENTING FEATURES (E.G., LATE AGE AT ONSET)
- 4) THE ABSENCE OF ALTERNATIVE EXPLANATIONS (E.G., MOOD/ANXIETY SYMPTOMS AS A PSYCHOLOGICAL REACTION TO THE GMC)

IF UNCLEAR: How much did (MOOD/ANXIETY SYMPTOMS) interfere with your life?

- E. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning
- D. The disturbance does not occur exclusively during the course of Delirium.



SCID-I (DSM-IV) Version 2.0	Substance-Induced (WHS 3/96)	Mood E	Episode	s		A.45
*SUBSTANCE -INDUCED MOOD/ANXIETY DISORDER*  IF SYMPTOMS NOT TEMPORALLY ASSOCIATED WITH SUBSTANCE, CHECK HEREAND RETURN TO EPISODE BEING EVALUATED.		Curr Past Dyst	ent MD MDE hymia ent GA	E	EVALU	A.1 A.12 A.38 F.31 J.8
CODE BASED ON INFORMATION ALREADY OBTAINED.	A. A prominent and persistent disturbance in mood/anxiety characterized by the following:					
	(1) depressed mood or markedly diminished interest or pleasure in all, or almost all, activities [FOR MOOD].	?	1	2	3	A194
	(2) prominent anxiety, panic attacks, obsession or compulsions [FOR ANXIETY]	?	1	2	3	A195
IF NOT KNOWN: When did the (MOOD/ANXIETY SYMPTOMS) BEGIN? (Were you already (SUBSTANCE) or had you just stopped or cut your use?	B. There is evidence from the history, physical examination, or laboratory findings that either (1) the symptoms in A developed during or within a month of substance Intoxication or withdrawal, or (2) medication use is etiologically related to the disturbance.	INDI TO E	UCED I	2 TANCI RETUR DE BEIN ED	N	A196
Do you think your (MOOD/ANXIETY SXS) are in any way related to your (SUBSTANCE USE)?  IF YES: Tell me how.  ASK ANY OF THE FOLLOWING QUESTIONS AS NEEDED TO RULE OUT A NON-SUBSTANCE-INDUCED ETIOLOGY:	C. The disturbance is not better accounted for by a Mood/Anxiety Disorder that is not substance-induced. Evidence that the symptoms are better accounted for by a Mood Disorder that is not substance-induced might include:	INDI TO E	UCED 1	2 TANCI RETUR DE BEIN ED	N	A197
IF UNKNOWN: Which came first the (SUBSTANCE USE) or the (MOOD/ANXIETY SYMPTOMS)?	precede the onset of the Substance					
IF UNKNOWN: Hove you had a	2) the ment of the second of					

IF UNKNOWN: Have you had a period of time when you stopped using (SUBSTANCE)?

2) the mood/anxiety symptoms persist for a substantial period of time (e.g., about a month after the cessation of acute withdrawal or

severe intoxication)

<sup>? =</sup> inadequate information

IF YES: After you stopped using (SUBSTANCE) did the (MOOD/ANXIETY SYMPTOMS) get better?

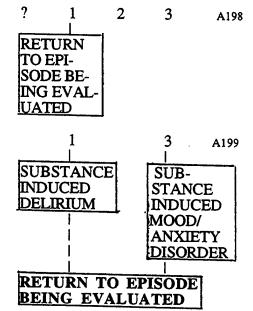
IF UNKNOWN: How much of (SUBSTANCE) were you taking when you began to have (MOOD/ANXIETY SYMPTOMS)?

IF UNKNOWN: Have you had any other episodes of (MOOD/ANXIETY SYMPTOMS)?

IF YES: How many? Were you taking (SUBSTANCES) at those times?

IF UNKNOWN: How much did (MOOD/ANXIETY SYMPTOMS) interfere with your life?

- 3) the mood symptoms are substantially in excess of what would be expected given the character, duration, or amount of the substance used
- 4) There is evidence suggesting the existence of an independent non-substance-induced Mood/Anxiety Disorder (e.g., a history of recurrent non-substance-related Major Depressive Episodes).
- E. The symptoms cause clinically significant distress or impairment in social, occupational, or their important areas of functioning.
- D. The disturbance does not occur exclusively during the course of Delirium.



### E. SUBSTANCE USE DISORDERS

# ALCOHOL USE DISORDERS (LIFETIME)

IF QUESTIONS J3, J4, J5, AND J6 FROM WHS QUESTIONNAIRE ANSWERED "NO," CHECK HERE\_\_\_\_\_ AND SKIP TO \*GENERAL ANXIETY DISORDER\*, F.31.

IF SCREENERS NOT USED OR IF ANY OF J3, J4, J5, OR J6 FROM WHS QUESTIONNAIRE ANSWERED "YES," CONTINUE:

What are your drinking habits like? (How much do you drink?)

When in your life were you drinking the most? (How long did that period last?)

During that time...

how often were you drinking?

RECORD DATE OF HEAVIEST USE AND DESCRIBE PATTERN:

what were you drinking? how much?

During that time...

did your drinking cause problems for you?

did anyone object to your drinking?

IF ALCOHOL DEPENDENCE SEEMS
LIKELY, CHECK HERE\_\_\_ AND
SKIP TO \*ALCOHOL DEPENDENCE\*,
E.4.

OTHERWISE, CONTINUE WITH \*ALCOHOL ABUSE\*
ON NEXT PAGE.

FI

## \*LIFETIME ALCOHOL ABUSE\*

# ALCOHOL ABUSE CRITERIA

Let me ask you a few more questions about your drinking habits.

Have you ever been intoxicated or high or very hung over while you were doing something important, like being at school or work, or taking care of children?

IF NO: What about missing something important, like staying away from school or work or missing an appointment because you were intoxicated, high, or very hung over?

> IF YES TO EITHER OF ABOVE: How often? (Over what period of time?)

Did you ever drink in a situation in which it might have been dangerous to drink at all? (Did you ever drive while you were really too drunk to drive?)

> IF YES AND UNKNOWN: How often? (Over what period of time?)

Has your drinking gotten you into trouble with the law?

> IF YES AND UNKNOWN: How often? (Over what period of time?)

IF NOT ALREADY KNOWN: Has your drinking caused you problems with other people, such as family members, friends, or people at work? (Have you ever gotten into physical fights or had bad arguments about your drinking?)

> IF YES: Did you keep on drinking anyway? (Over what period of time?)

A. A maladaptive pattern f substance use leading to clinically significant impairment or distress. as manifested by one (or more) of the following occurring within a twelve month period:

(1) recurrent alcohol use resulting in a failure to fulfill major role obligations at work, school, or home (e.g., repeated absences or poor work performance related to alcohol use; alcohol-related absences, suspensions, or expulsions from school; neglect of children or household)

(2) recurrent alcohol use in automobile or operating a machine when impaired by alcohol use)

(3) recurrent alcohol-related legal problems (e.g., arrests for alcoholrelated disorderly conduct)

(4) continued alcohol use despite having persistent or recurrent social or interpersonal problems caused or exacerbated by the effects of alcohol (e.g., bad arguments with spouse about consequences of intoxication, physical fights)

situations in which it is physically hazardous (e.g., driving an

1

1

?

?

?

1

2

3

3

3

E3

E4

E5

1

2

3

? = inadequate information

1 = absent or false

2 =subthreshold

3 =threshold or true

**E**6

AT LEAST ONE "A" ITEM CODED "3"

?

1

3

IF NO POSSIBILITY OF PHYSIOLOGICAL DEPENDENCE OR COMPULSIVE USE, GO TO \*GENERALIZED ANXIETY **DISORDER,\* F.31.** OTHERWISE, CONTINUE ASKING ABOUT DEPENDENCE, E.4.

> ALCOHOL ABUSE. CONTINUE ASKING ABOUT DEPEND-ENCE E.4

# ALCOHOL DEPENDENCE

# ALCOHOL DEPENDENCE CRITERIA

I'd now like to ask you some more questions about your drinking habits.

A maladaptive pattern of alcohol use, leading to clinically significant impairment or distress, as manifested by three (or more) of the following occurring at any time in the same twelve month period:

NOTE: CRITERIA FOR ALCOHOL DEPENDENCE ARE NOT IN DSM IV ORDER

Have you often found that when you started drinking you ended up drinking more than you were planning to?

(3) alcohol is often taken in larger amounts OR over a longer period than was intended

? 1 2 3 E7

3

E8

IF NO: What about drinking for a much longer period of time than you were planning to?

Have you tried to cut down or stop drinking alcohol?

IF YES: Did you ever actually stop drinking altogether?

(How many times did you try to cut down or stop altogether?)

IF NO: Did you want to stop or cut down? (Is this something you kept worrying about?)

Have you spent a lot of time drinking, being high, or hung over?

Have you had times when you would drink so often that you started to drink instead of working or spending time at hobbies or with your family or friends? (4) there is a persistent desire OR unsuccessful efforts to cut down or control substance use

(5) a great deal of time is spent in activities necessary to obtain alcohol, use alcohol, or recover from its effects

(6) important social, occupational, or recreational activities given up or reduced because of alcohol use

? 1 2 3 E10

2

3

**E**9

1

?

1

1

?

1

2

2

Ei1

E12

3

3

E13

E14

3

IF NOT ALREADY KNOWN: Has your drinking ever caused any psychological problems like making you depressed or anxious, making it difficult to sleep, or causing "blackouts?"

IF NOT ALREADY KNOWN: Has your drinking ever caused significant physical problems or made a physical problem worse?

IF YES TO EITHER OF THE ABOVE: Did you keep on drinking anyway?

Have you found that you needed to drink a lot more in order to get the feeling you wanted than you did when you first started drinking?

IF YES: How much more?

IF NO: What about finding that when you drank the same amount, it had much less effect than before?

Have you ever had any withdrawal symptoms when you cut down or stopped drinking like...

...sweating or racing heart?

...hand shakes?

...trouble sleeping?

...feeling nauseated or vomiting?

...feeling agitated?

...or feeling anxious?

(How about having a seizure or seeing, feeling, or hearing things that weren't really there?)

IF NO: Have you ever started the day with a drink, or did you often drink to keep yourself from getting the shakes or becoming sick?

(7) alcohol use is continued despite knowledge of having a persistent or recurrent physical problem that is likely to have been caused or exacerbated by alcohol (e.g., continued drinking despite recognition that an ulcer was made worse by alcohol consumption)

(1) tolerance, as defined by either of the following:

(a) a need for markedly increased amounts of alcohol to achieve intoxication or desired effect

(b) markedly diminished effect with continued use of the same amount of alcohol

(2) withdrawal, as manifested by either (a) or (b):

(a) at least <u>TWO</u> of the following:

-- autonomic hyperactivity (e.g., sweating or pulse rate greater than 100)

-- increased hand tremor

-- insomnia

-- nausea or vomiting

-- psychomotor agitation

-- anxiety

-- grand mal seizures

 transient visual, tactile, or auditory hallucination or illusions

(b) alcohol (or a substance from the sedative/ hypnotic/anxiolytic class) taken to relieve or avoid withdrawal symptoms

? = inadequate information

1 = absent or false

2 =subthreshold

3 =threshold or true

E15

IF UNKNOWN: When did (SXS CODED "3" ABOVE) occur? (Did they all happen around the same time?)

AT LEAST THREE "A" ITEMS CODED "3" AND ITEMS OCCURRED WITHIN THE SAME TWELVE (12) MONTH PERIOD

Indicate if:

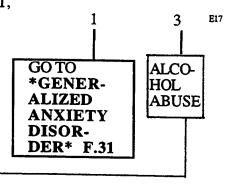
1 - With Physiological Dependence
(current evidence of tolerance or withdrawal)

2- Without Physiological Dependence
(no current evidence of tolerance or withdrawal)

GO TO DEPENDENCE CHRONOLOGY, E.7

IF ALCOHOL ABUSE QUESTIONS (PAGES E.1-E.3) HAVE <u>NOT</u> YET BEEN ASKED, GO TO PAGE E.1 AND CHECK FOR ABUSE.

IF ABUSE QUESTIONS HAVE BEEN ASKED AND ABUSE IS PRESENT, CODE "3"; OTHERWISE, IF QUESTIONS HAVE BEEN ASKED AND ABUSE IS NOT PRESENT, GO TO \*GENERALIZED ANXIETY DISORDER F.31.



ALCOHOL

How old were you when you first had (ABUSE SXS CODED "3")?

Age at onset of Alcohol Abuse (CODE 99 IF UNKNOWN)

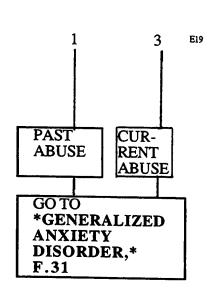
----

E18

IF UNCLEAR: During the past month, have you had anything at all to drink?

IF YES: Tell me more about it. (Has your drinking caused you any problems?)

Criteria for Alcohol Abuse met at any time in past month



E20

E22

## \*CHRONOLOGY FOR DEPENDENCE\*

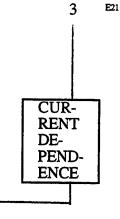
How old were you when you first had (LIST OF ALCOHOL DEPENDENCE OR ABUSE SXS CODED "3")?

Age at onset of Alcohol Dependence or Abuse (CODE 99 IF UNKNOWN)

IF UNCLEAR: During the past month, have you had anything at all to drink?

IF YES: Tell me more about it. (Has your drinking caused you any problems?)

Full criteria for Alcohol
Dependence met at any time in past
month (or never had a month
without symptoms of Dependence
or Abuse since onset of
Dependence)



1

# \*SEVERITY SPECIFIERS FOR DEPENDENCE\*

NOTE SEVERITY OF DEPENDENCE FOR WORST WEEK OF PAST MONTH (Additional questions about the effect of alcohol on social and occupational functioning may be necessary.)

1-Mild:

Few, if any, symptoms in excess of those required to make the diagnosis, and the symptoms result in no more than mild impairment in occupational functioning or in usual social activities or relationships with others (or criteria met for Dependence in the past and some current problems).

2-Moderate:

Symptoms or functional impairment between "mild" and

"severe."

3-Severe:

Many symptoms in excess of those required to make the diagnosis, and the symptoms markedly interfere with occupational functioning or with usual social activities or relationships with others.

GO TO \*GENERALIZED ANXIETY DISORDER, F.31\*

F135

#### \*GENERALIZED ANXIETY DISORDER\* (CURRENT ONLY)

## GENERALIZED ANXIETY DISORDER CRITERIA

In the past six months, was there a period when you were particularly nervous or anxious?

Do you also worry a lot about bad things that might happen?

IF YES: What do you worry about?(How much do you worry about [EVENTS OR ACTIVITIES])

A. Excessive anxiety and worry (apprehensive expectation), occurring more days than not for at least six months, about a number of events or activities (such as work or school performance)

? 1 GOTO \*MIXED ANXIETY DISOR-DER,\* J.5 2

2

2

3

During the last six months, would you say that you have been worrying (more days than not?)

When you're worrying this way, do you find that you can't stop yourself?

B. The person finds it difficult to control the worry

? 1 GO TO \*MIXED ANXIETY DISOR-DER,\* J.5 F136

F137

3

3

When did this anxiety start? COMPARE ANSWER WITH ONSET OF MOOD OR PSYCHOTIC DISORDER.

F(2). Does not occur exclusively during the course of a Mood Disorder, Psychotic Disorder, or a Pervasive Developmental Disorder ? 1 GO TO \*MIXED ANXIETY DISOR-DER,\* J.5

SCID Version 2.0 (For DSM-IV)	GAD	(WHS 3/96)	Anxiety D	isorders	:		F.32
Now I am going to ask you some questions about other symptoms that often go along with being nervous.	associate following least som	nxiety and worry are d with at least three of the such symptoms (with symptoms present for the past street than not for the past street.	at r	·			
Thinking about those periods in the past six months when you're feeling nervous or anxious							
do you often feel physically restless can't sit still?	(1) restle	essness or feeling keyed edge	! ?	1	2	3	F138
do you often feel keyed up or on edge?							
do you often tire easily?	(2) being	easily fatigued	?	1	2	3	F139
do you have trouble concentrating or does your mind go blank?	(3) diffic mind goin	ulty concentrating or ng blank	?	1	2	3	F140
are you often irritable?	(4) irrital	oility	?	1	2	3	F141
are your muscles often tense?	(5) musc	le tension	?	1	2	3	F142
do you often have trouble falling or staying asleep?	(6) sleep falling or unsatisfyi	disturbance (difficulty staying asleep, or restleing sleep)	? ess	1	2	3	F143
	AT LEAS	ST THREE "C" SXS AI "3"	RE GOT			3	F144

DISOR-DER,\* J.5

F145

CODE BASED ON PREVIOUS INFORMATION.

D. The focus of the anxiety and worry is not confined to the features of another Axis I Disorder, e.g. being embarrassed in public (as in Social Phobia), being contaminated (as in Obsessive-Compulsive Disorder), being away from home or close relatives (as in Separation Anxiety Disorder), gaining weight (as in Anorexia Nervosa), or having a serious illness (as in Hypochondriasis), and is not part of Posttraumatic Stress Disorder.

? 1 GO TO \*MIXED ANXIETY DISOR-DER.\* J.5

IF UNCLEAR: What effect has the anxiety, worry, or (PHYSICAL SYMPTOMS) had on your life? (Has it made it hard for you to do your work or be with your friends?)

E. The anxiety, worry, or physical symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning

? 1 2 3 F146
GO TO
\*MIXED
ANXIETY
DISORDER,\* J.5

Just before you began having this anciety, were you taking any drugs, stimulants or medicines?

(How much coffee, tea, or cola do you drink a day?)

Just before these problems began, were you physically ill?

IF YES: What did the doctor say?

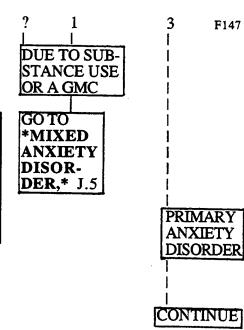
F. Not due to the direct psychological effects of a substance (e.g., a drug of abuse, medication) or to a general medical condition

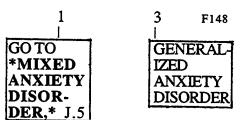
IF A GENERAL MEDICAL
CONDITION OR SUBSTANCE
MAY BE ETIOLOGICALLY
ASSOCIATED WITH THE
ANXIETY, GO TO
\*SUBSTANCE /GMC\*, A.43
RETURN HERE TO MAKE
RATING OF "1" OR "3".

Etiological general medical conditions include: hyper- and hypo-thyroidism, hypoglycemia, hyperparathyroidism, pheochromocytoma, congestive heart failure, arrhythmias, pulmonary embolism, chronic obstructive pulmonary disease, B-12 deficiency, porphyria, CNS neoplasms, vestibular dysfunction, encephalitis.

Etiological substances include: intoxicants with central nervous stimulants (e.g., cocaine, amphetamines, caffeine) or cannabis, hallucinogens, PCP, or alcohol, or withdrawal from central nervous system depressants (e.g., alcohol, sedatives, hypnotics) or cocaine

GENERALIZED ANXIETY CRITERIA A,B,C,D,E,AND F ARE CODED "3"





### \*CHRONOLOGY OF GENERALIZED ANXIETY DISORDER\*

#### INDICATE CURRENT SEVERITY:

- 1-- Mild: Few, if any, symptoms in excess of those required to make the diagnosis are present, and symptoms result in no more than minor impairments in social or occupational functioning.
- 2-- Moderate: Symptoms or functional impairment between "mild" and "severe" are present.
- 3-- Severe: Many symptoms in excess of those required to make the diagnosis, or several symptoms that are particularly severe, are present, or the symptoms result in marked impairment in social or occupational functioning.

#### \*AGE AT ONSET\*

IF UNKNOWN: How old were you when you first started having (SXS OF GAD)?

Age at onset of Generalized Anxiety Disorder (CODE 99 IF UNKNOWN)

F149

GO TO \*MIXED ANXIETY DISORDER\* J.5.

120

#### \*MAD\*

#### MIXED ANXIETY DISORDER CRITERIA (APPENDIX CATEGORY)

IF: CRITERIA HAVE EVER BEEN MET FOR MAJOR DEPRESSIVE DISORDER, DYSTHYMIC DISORDER, PANIC DISORDER, OR GENERALIZED ANXIETY DISORDER, CHECK HERE AND END SCID INTERVIEW.

IF: CRITERIA ARE CURRENTLY MET FOR ANY OTHER ANXIETY OR MOOD DISORDER (INCLUDING AN ANXIETY DISORDER OR MOOD DISORDER IN PARTIAL REMISSION), CHECK HERE\_ AND END SCID INTERVIEW.

During the past month, have you been feeling bad...that is depressed or anxious for most of the time?

A. Persistent or recurrent dysphoric mood lasting at least one month.

DONE

During those times when you're feeling bad...

B. The dysphoric mood is accompanied by at least 1 month of four (or more) of the following symptoms:

NOTE: FOR EACH OF THE FOLLOWING, MAKE SURE THE SYMPTOM LASTED AT LEAST 1 MONTH

...have you had trouble concentrating or does your mind go blank?

(1) difficulty concentrating or mind going blank

? 1 2 J21 3

...have you had trouble sleeping?

(2) sleep disturbance (difficulty falling or staying asleep, or restless unsatisfying sleep)

? 1 2 3 **322** 

...have you felt like you were tired all the time or that your energy was low?

(3) fatigue or low energy

? 1 2 3 **J**23

...have you felt irritable or cranky? ...did you worry a lot about things? (4) irritability

1 2 3 **J24** 

...did you find yourself crying over little

(5) worry

? 2 1 3 325

3

**J**26

**J**27

?

?

1

things?

(6) easily moved to tears

2

...have you been watchful or on guard even when there is no reason to be?

(7) hypervigilance

SCID-I (DSM-IV) Version 2.0 MAD	(WHS 3/96)				J.	6
when looking ahead, were you expecting the worst?	(8) anticipating the worst	?	1	2	3	J28
did you feel hopeless about the future?	(9) hopeless (pervasive pessimism about the future)	?	1	2	3	129
did you feel down on yourself or that you were worthless?	(10) low self-esteem or feelings of worthlessness	?	1	2	3	<b>J3</b> 0
	AT LEAST FOUR "B" SYMPTOMS CODED "3"	?	1 I DONE		3	J31
IF UNCLEAR: How much did these bad feelings interfere with your life?	C. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.	?	1           	2	3	J32

Just before you began having these symptoms, were you taking any drugs, stimulants or medicines?

(How much coffee, tea, or cola do you drink a day?)

Just before these problems began, were you physically ill? (What did the doctor say?)

D. Not due to the direct physiological effects of a substance (e.g., a drug of abuse, medication) or to a general medical condition

IF A GENERAL MEDICAL
CONDITION OR SUBSTANCE
MAY BE ETIOLOGICALLY
ASSOCIATED WITH THE
ANXIETY, GO TO
\*GMC/SUBSTANCE\*, A.43
AND RETURN HERE TO MAKE
RATING OF "1" OR "3."

Etiological general medical conditions include: hyper- and hypo-thyroidism, hypoglycemia, hyper-parathyroidism, pheochromocytoma, congestive heart failure, arrythmias, pulmonary disease, pneumonia, hyperventilation, B-12 deficiency, porphyria, CNS neoplasms, vestibular dysfunction, encephalitis.

Etiological substance include: intoxication with central nervous stimulants (e.g., cocaine, amphetamines, caffeine) or cannabis, hallucinogens, PCP, or alcohol, or withdrawal from central nervous system depressants (e.g., alcohol, sedatives, hypnotics) or from cocaine.

#### E. All of the following:

- (1) Has never met criteria for Major Depressive Disorder, Dysthymic disorder, Panic Disorder, or Generalized Anxiety Disorder.
- (2) Does not currently meet criteria for any other Anxiety or Mood Disorder (including an Anxiety or Mood Disorder in partial remission)
- (3) Not better accounted for by any other mental disorder

1 3 **J33 DUE TO** SUBSTANCE USE OR A GMC. DONE. **PRIMARY** ANXIETY DISORDER CONTI-NUE J34 3

DONE

J36

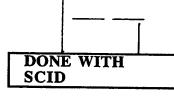
CRITERIA A, B, C, D, AND E ARE CODED "3"

3 ISS | | MIXED | ANXIETY | DEPRES-| SIVE DIS-| ORDER

#### \*AGE AT ONSET\*

IF UNKNOWN: How old were you when you first started having (SXS OF MAD)?

Age at onset of Mixed Anxiety Depressive Disorder (CODE 99 IF UNKNOWN)



		$\neg$ $\sqcap$			
				_	
L	L		 L		





# WOMEN'S HEALTH STUDY

Interim Questionnaire

As you may already know, there are two components to this breast cancer research--a study of the biology of genetics, which is now located at the University of Pennsylvania (previously it was at the University of Michigan) and a study of the personal and social aspects of genetic testing which is located at the University of Michigan. This questionnaire is part of the study of personal and social aspects. Some of these questions will be familiar. We are asking them again to learn more about how feelings and attitudes change over time.

If you have any questions about this questionnaire or research, please feel free to call me at 313-998-6560. For questions about the genetic testing component, you may call Kathleen Calzone at the University of Pennsylvania, 215-349-8141. Thank you very much for your valuable participation in this research.

Sean Bouvrette Project Manager Women's Health Study University of Michigan

TOD	DAYS DATE				ш	
			INTERIM QUEST	TIONNAIRE - A		
		GENE	TIC TEST	<b>ING-SECT</b>	ON 1	
1.	Have you cor project?	ntributed a blo	od or tissue sample	to the GENETIC T	FESTING portion of the	research
	r -3		□ Yes □ N	О		B21.
2.				blood or tissue sam	ple to the <u>GENETIC T</u>	<u>ESTING</u>
	portion of the	research proje	cct? ☐ Yes ☐ N	lo 🗆 I Don't K	Know	B22.
3.	Have you or a	any family me	mbers received noti	fication that genetic	c results are available?	B23.
	]	There Has Been No otification	Results Are Available	Results Are NOT YET Available	Results will NEVER BE Available, I am Not Eligible	
4.	Have you record Yes  4a.  4b.	When did the What was the Universit	of genetic testing for o (Skip to Question is occur?  ne source of this information of Pennsylvania the results? (Options)	ormation?	mo/yr)	
5.	Has <b>any fam</b> □ Ye	•	eceived results of a contract of second (Skip to Next Second )	•	breast or ovarian cancer n't Know (Skip to Next	
	5a.	When did th	is occur?	(r	mo/yr)	
	5b.		ne source of this inf ry of Pennsylvania		Testing □Other:	
	5c.	What were t	he results? (Option	al)		
	5d.	able to figur	re out whether you a for breast cancer wi	are positive or nega		

### PERSONAL ATTITUDES SECTION

1. For each of these statements, please indicate the extent to which you agree or disagree by circling the appropriate number. There are no right or wrong answers. We are only interested in your opinions.

		Strong Disagr	gly ree			rongly Agree	
a.	If you don't have your health, you don't have anything.	1	2	3	4	5	L5a.
b.	There are many things I care about more than my health.		2	3	4	5	L5b.
c.	Good health is of only minor importance in a happy life.	1	2	3	4	5	L5c.
d.	There is nothing more important than good health.	1	2	3	4	5	L5d.
e.	In uncertain times, I usually expect the best.	1	2	3	4	5	E1.
f.	It's easy for me to relax.	1	2	3	4	5	E2.
g.	If something can go wrong for me, it will.	1	2	3	4	5	E3.
h.	I always look on the bright side of things.	1	2	3	4	5	E4.
i.	I'm always optimistic about my future.	1	2	3	4	5	E5.
j.	I enjoy my friends a lot.	1	2	3	4	5	E6.
k.	It's important for me to keep busy.	1	2	3	4	5	E7.
1.	I hardly ever expect things to go my way.	1	2	3	4	5	E8.
m.	Things never work out the way I want them to.	1	2	3	4	5	E9.
n.	I don't get upset too easily.	1	2	3	4	5	E10.
0.	I'm a believer in the idea that "every cloud has a silver lining."		2	3	4	5	E11.
p.	I rarely count on good things happening to me.	1	2	3	4	5	E12.

## **GENETIC TESTING-SECTION 2**

`	ase check <u>one</u>	• •	ka taat imamaadia	4al	
(1)				•	ecomes available
(2)		definitely take t	•		•
(3)		•		•	comes available
(4)	_	probably take th		•	
(5)		<u>indecided</u> wheth		ie test	
(6)		<u>probably not</u> tal			
7)	I will	definitely not ta	ke the test.		
ou i	nay be at increas	sed fisk for brea	si cancer becau	se of your rain	my mstory?
	Not At All Distressing				Very Distressing
<b>T</b>	Distressing 1	2	3	4	Distressing 5
	Distressing  1  distressing it is litered gene associ	to be given the	opportunity to b	oe tested for th	Distressing 5 ne BRCA-1 gene Very
	Distressing  1  distressing it is tered gene associated.	to be given the	opportunity to b	oe tested for th	Distressing 5 ne BRCA-1 gene
the all	Distressing  1  distressing it is litered gene associated to the control of the c	to be given the ciated with incre	opportunity to be ased risk for brown	pe tested for the east cancer?	Distressing  5 ne BRCA-1 gene  Very Distressing

Distressed				Distressed
1	2	3	4	5

6.	How distressed would you be if you took the test and found that you did not have
	the BRCA-1 gene?

Not At All Distressed				Very Distressed
1	2	3	4	5

7. Overall, to what extent do you welcome the opportunity to be tested for the BRCA-1 gene?

B71.

B70.

Not At All				Very Much So
1	2	3	4	5

		Not A	t All		All Th	e Time
8.	How often do you worry about again developing breast cancer?	1	2	3	4	5
9.	To what extent do these worries interfere with your every day life?	1	2	3	4	5
10.	How often do you worry about having the altered gene carrying risk for breast cancer?	1	2	3	4	5
11.	To what extent do these worries you have about having this altered gene interfere with your every day life?		2	3	4	5

B27.

B28.

B29.

B30.

12. Before your diagnosis of breast cancer, how likely did you think you were to develop breast cancer, compared to other women? (Please circle one)

B7.

Much Les Likely	s		M	uch More Likely
1	2	3	4	5

10	X	.1 1 .	. •		1 0
13.	When was	the last	time you	had a	mammography?

Month \_\_\_\_Year

B32.

14.	How many times have you conducted a breast self-examinations (BSE) in the

past six months?			

B33.

nes

(-8)  $\square$  This question does not apply because of surgery.

(-8) This question does not apply because of surgery.

15.	How confident are you that you will perform breast self examination (BSE)										
	15a.	as f <b>reque</b>	ently as	needed?	(-8) $\square$ D	oes Not	Apply I	Because of Surgery	B34a.		
		Not at All	2	3	4	5	6	Very Much So 7			
	15b.	as carefu	-as frequently as needed? (-8) $\square$ Does Not Apply Because of Surgery  Not at All  1 2 3 4 5 6 7  -as carefully and competently as needed?  (-8) $\square$ Does Not Apply Because of Surgery	B34b.							
		Not at All	2	2	4	~		Very Much So			

For each of the following areas of your life, you will asked to make <u>two</u> ratings. First, indicate how much these decisions have been affected by <u>the possibility that you have an increased risk for breast cancer</u> (based on your family history). Second, how much would these decisions be affected by <u>the results of genetic testing</u>?

1	2	3	4	5
Not at all affe	cted			Very much affected

				affecte or bred		_	Would be affected by the results of genetic testing					
16.	Decisions about having children	1	2	3	4	5	1	2	3	4	5	B: B:
17.	Decisions about form of birth control	1	2	3	4	5	1	2	3	4	5	B: B:
18.	Decisions about which steps to take to prevent the recurrence of breast cancer	1	2	3	4	5	1	2	3	4	5	B: B:
19.	Decisions about work and career	1	2	3	4	5	1	2	3	4	5	B: B:
20.	Decisions about savings and financial planning	1	2	3	4	5	1	2	3	4	5	B: B:
21.	Decisions about plans for the future	1	2	3	4	5	1	2	3	4	5	B. B.

22.	Answer	the	following	question	only	if	you	have	daughters.	

☐ Does Not Apply
(Skip to Next Section, Life Events)

B41.

			e been gh risk	Would be affected by the results of genetic testing								
a	Plans for your daughter's future	1	2	3	4	5	1	2	3	4	5	B42: B421

## **LIFE EVENTS SECTION**

	You retired, were fired, or laid off from work.	g.	A close family member was seriously ill or injured.
	You were unemployed and looking for work.	h.	You had a marital separation or divorce.
	Your spouse retired, was fired, or laid off from work.	i.	You had serious troubles with relatives or close friends.
	Your spouse was unemployed and looking for work.	j.	Your spouse had troubles or difficulties with relatives or close
	You had problems with the police or		friends.
	court.	k.	A close family member died.
	You got into serious financial	1.	A close friend or relative died.
	difficulties.	m.	You were seriously ill or injured.

### **MARRIAGE SECTION**

The following questions apply to persons who are <u>married or living with</u> a partner. If you are not married or living with a partner, check the appropriate box and please skip to the Next Section, MOOD.

Not married or living with a partner	Ηa
<u> </u>	

Most persons have disagreements in their relationships. Please check the appropriate box to indicate the extent of agreement or disagreement experienced between you and your partner **DURING THE PAST MONTH**, regarding.

		Always Agree	Almost Always Agree	Occa- sionally Disagree	Fre- quently Disagree	Almost Always Disagree	Always Disagree	
1.	Religious matters	6	5	4	3	2	1	Н3.
2.	Demonstration of affection	6	5	4	3	2	1	H4.
3.	Sex relations	6	5	4	3	2	1	Н6.
4.	Conventionality (correct or proper behavior)	6	5	4	3	2	1	Н7.
5.	Making major decisions	6	5	4	3	2	1	H12.
6.	Career decisions	6	5	4	3	2	1	H15.

		All of the time	Most of the time	More often than most	Occa- sionally	Rarely	Never	
7.	How often do you discuss or have you considered divorce, separation, or terminating your relationship?	1	2	3	4	5	6	H16.
8.	Do you ever regret that you married (or are living together)?	1	2	3	4	5	6	H20.
9.	How often do you and your husband/partner quarrel?	1	2	3	4	5	6	H21.
10.	How often do you and your husband/partner "get on each other's nerves?"	1	2	3	4	5	6	H22.

	All of	Most of	Some of	Very few	None of
	Them	Them	Them	of Them	Them
11. Do you and your husband/partner engage in outside interests together?	5	4	3	2	1

H24.

How often would you say the following events occur between you and your husband/partner?

		Never	Less than once a month	About twice a month	About twice a week	Once a day	More Often
12.	Have a stimulating exchange of ideas	1	2	3	4	5	6
13.	Calmly discuss something	1	2	3	4	5	6
14.	Work together on a project	1	2	3	4	5	6

H25.

H27.

H28.

15. Considering only the positive feelings you have toward your husband/partner, and ignoring the negative ones, please rate how positive these feelings are:

H33.

Not A Posi									emely sitive
1	2	3	4	5	6	7	8	9	10

16. Considering only the negative feelings you have toward your husband/partner, and ignoring the positive ones, please rate how negative these feelings are:

H34.

Not A Nega									emely gative
1	2	3	4	5	6	7	8	9	10

17. The following questions concern your husband's involvement in your health care.

		Never				Very Often	
a.	How often does your husband/partner go with you to your appointments with doctors?	1	2	3	4	5	H35a.
b.	How often does your husband/partner talk with your doctor or other medical personnel about your risk for breast cancer?	1	2	3	4	5	Н35Ь.
c.	How often does your husband/partner keep track of what you need to do about your risk for breast cancer?	1	2	3	4	5	Н35с.
d.	How often does your husband/partner change his activities to assist you in your health care?	1	2	3	4	5	H35d.

18.	Has your husband/informed about you	partner a ir risk fo	r breast o	ndividua cancer an	d what	can be do	o sessions to become ne?	Н36.
19.	How much contact concerning your ris				had wit	th medical	personnel	Н37.
	Very Little or None 1	2	3	4	5	6	A lot 7	
20.	Do you feel your hi cancer and what can	usband/p n be done	artner is e about i	adequate t?	ely infor	med conc	erning your risk for breast	Н38.
	Not at All	2	3	4	5	6	Very Much 7	

To what extent are you satisfied with your husband/partner's involvement in your health care? Not at All Very Much 7 2 3 4 5

H39.

21.

## **MOOD SECTION**

1.	blue,		our meame had two weeks or more when hearly every day you for in which you lost all interest in things like work or hobbies or thing for fun?	
		(1) □ Yes	(5) $\square$ No (Skip to Question 2)	I14
	1a.	If there was	such a two-week period, did your work or relationships suffer?	I14a.
		(1) □ Yes	(5) □ No	
	1b.	If there was s psychotherap	such a two-week period, did you get counseling or by?	I14b.
		(1) □ Yes	(5) □ No	
	1c.	If there was for this condi	such a two-week period, did you get medication tion?	I14c.
		(1) □ Yes	(5) □ No	
2.	felt sa	ıd, blue, or depi	ns, have you had two weeks or more when nearly every day you ressed or in which you lost all interest in things like work or u usually liked to do for fun?  (5) \( \subseteq \text{No (Skip to Question 3)} \)	I12.
	2a.		such a two-week period in the past 6 months, did relationships suffer?	I12a.
		(1) □ Yes	(5) □ No	
	2b.		such a two-week period in the past 6 months, did you get psychotherapy?	I12b.
		(1) ☐ Yes	(5) □ No	
	2c.		such a two-week period in the past 6 months, did you get or this condition?	I12c.
		(1) □ Yes	(5) □ No	
3.		ou <b>currently</b> reotional problem	eceiving counseling, psychotherapy or medication for depression as?	113.
		(1) □ Yes	(5) □ No	

### **STRAIN SECTION**

LISTED BELOW ARE SOME SYMPTOMS OF STRAIN THAT PEOPLE SOMETIMES HAVE. Please Read Each One Carefully And Check The Answer Which Best Reflects How Much That Symptom Has Bothered You During the <u>Past Three Months</u>.

		Not at all	<u>A little</u>	<u>Quite a bit</u>	<u>Extremely</u>	
1.	Suddenly scared for no reason	1	2	3	4	K1.
2.	Feeling fearful	1	2	3	4	K2.
3.	Faintness, dizziness, or weakness	1	2	3	4	K3.
4.	Nervousness or shakiness inside	1	2	3	4	K4.
5.	Heart pounding or racing	1	2	3	4	K5.
6.	Trembling	1	2	3	4	K6.
7.	Feeling tense or keyed up	11	2	3	4	K7.
8.	Headaches	11	2	3	4	K8.
9.	Spells of terror or panic	11	2	3	4	K9.
10.	Feeling restless, can't sit still	1	2	3	4	K10.
11.	Feeling low in energyslowed down	1	2	3	4	K11.
12.	Blaming yourself for things	1	2	3	4	K12.
13.	Crying easily	1	2	3	4	K13.
14.	Loss of sexual interest or pleasure	1	2	3	4	K14.
15.	Poor appetite	1	2	3	4	K15.
16.	Difficulty falling asleep, staying asleep	1	2	3	4	K16.
17.	Feeling hopeless about the future	1	2	3	4	K17.
18.	Feeling blue	1	2	3	4	K18.
19.	Feeling lonely	1	2	3	4	K19.
20.	Feeling trapped or caught	1	2	3	4	K20.
21.	Worrying too much about things	1	2	3	4	K21.
22.	Feeling no interest in things	1	2	3	4	K22.
23.	Thoughts of ending your life	1	2	3	4	K23.
24.	Feeling everything is an effort	1	2	3	4	K24.
25.	Feelings of worthlessness	1	2	3	4	K25.

## **COPING SECTION**

1. Sometimes people can find unexpected benefits in difficulties. We are interested in the ways in which you might have made positive use of your risk for breast cancer. For each of the statements below, indicate the degree to which your life is affected <u>positively</u> by your risk of breast cancer.

		Not At All	A Very Small Degree	A Small Degree	A Moderate Degree	A Great Degree	A Very Great Degree	
a.	My priorities about what is important in life.	1	2	3	4	5	6	L6a.
b.	I'm more likely to try to change things which need changing.	1	2	3	4	5	6	L6b.
c.	An appreciation for the value of my own life.	1	2	3	4	5	6	L6c.
d.	A feeling of self-reliance.	1	2	3	4	5	6	L6d.
e.	A better understanding of spiritual matters.	1	2	3	4	5	6	L6e.
f.	Knowing that I can count on people in times of troubles.	1	2	3	4	5	6	L6f.
g.	A sense of closeness with others.	1	2	3	4	5	6	L6g.
h.	Knowing I can handle difficulties.	1	2	3	4	5	6	L6h.
i	A willingness to express my emotions.	1	2	3	4	5	6	L6i.
j.	Being able to accept the way things work out.	1	2	3	4	5	6	L6j.
k.	Appreciating each day.	1	2	3	4	5	6	L6k.
1.	Having compassion for others.	1	2	3	4	5	6	L61.
m.	I'm able to do better things with my life.	1	2	3	4	5	6	L6m.
n.	New opportunities are available which wouldn't have been otherwise.	1	2	3	4	5	6	L6n.

2. This set of questions deals with ways you've been coping with the stress in your life that comes with being at risk for breast cancer. There are many ways people try to deal with problems. Obviously, different people deal with things in different ways, but we are interested in how you've tried to deal with it. Each item says something about a particular way of coping. We 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 it seems to be working but just whether or not you're doing it. Use these response choices below and try not to let one answer influence another. Make your answers as true FOR YOU as you can.

		I haven't been doing this at all 1	I've been doing this a little bit 2	I've been doing this some 3	I've been doing this a lot 4
a.	I've been turning to work or other activities to take my mind off things.	1	2	3	4
b.	I've been concentrating my efforts on doing something about my situation.	1	2	3	4
c.	I've been saying to myself "this isn't possible."	1	2	3	4
d.	I've been using alcohol or other drugs to make myself feel better.	1	2	3	4
€.	I've been getting emotional support from others.	1	2	3	4
f.	I've been giving up trying to deal with it.	1	2	3	4
3.	I've been taking action to try to make the situation better.	1	2	3	4
h.	I've been refusing to believe that it is possible that I have the gene.	1	2	3	4
	I've been saying things to let my unpleasant feelings escape.	1	2	3	4
•	I've been using alcohol or other drugs to help me get through it.	1	2	3	4
k.	I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4
•	I've been trying to come up with a strategy about what to do.	1	2	3	4
m.	I've been getting comfort and understanding from someone.	1	2	3	4

		I haven't been doing this at all	I've been doing this a little bit 2	I've been doing this some 3	I've been doing this a lot 4
n.	I've been giving up the attempt to cope.	1	2	3	4
0.	I've been accepting the possibility that I might have the gene.	1	2	3	4
р.	I've been expressing my negative feelings.	1	2	3	4
q.	I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4
•	I've been learning to live with the possibility that I might have the gene.	1	2	3	4
· .	I've been thinking hard about what steps to take.	1	2	3	4
t.	I've been praying or meditating.	1	2	3	4
u.	I've been making fun of the situation.	1	2	3	4

The following items are to be answered only by those women who are <u>married or living with a partner</u>.
 (-8) □ Not married or living with a partner
 (Skip to Last Section on page 15, Background Data)

		I haven't been doing this at all 1	I've been doing this a little bit 2	I've been doing this some 3	I've been doing this a lot 4	
a.	I've been denying or hiding my anger around my husband/partner.	1	2	3	4	L8a
b.	I've been denying or hiding my worries around my husband/partner.	1	2	3	4	L8b
c.	I've been avoiding talking about my problems around my husband/partner.	1	2	3	4	L8c
d.	I've acted more positive around my husband/partner than I feel.	1	2	3	4	L8d

### **BACKGROUND DATA**

These are a few questions about your religious background, that we forgot to ask on the original questionnaire.

1.	Religion	1:	Catholic Jewish Muslim	(1)	Protestant Buddhist Other None	(4) ☐ (5) ☐ (6) ☐ (7) ☐	А3.
	1a.	How often do you (1) □ Less Often Ti		(5)	)	A Month or More	A3a.
	1b.	How important	are religious a	nd spiritual l	peliefs in your li	fe?	A3b.
		Not at All	2	3	Ver	ry Important 5	

Once Again, We thank you for all of your valued participation in this study.

			_	
لـــــا	 L	L		





# WOMEN'S HEALTH STUDY

Interim Questionnaire

As you may already know, there are two components to this breast cancer research--a study of the biology of genetics, which is now located at the University of Pennsylvania (previously it was at the University of Michigan) and a study of the personal and social aspects of genetic testing which is located at the University of Michigan. This questionnaire is part of the study of personal and social aspects. Some of these questions will be familiar. We are asking them again to learn more about how feelings and attitudes change over time.

If you have any questions about this questionnaire or research, please feel free to call me at 313-998-6560. For questions about the genetic testing component, you may call Kathleen Calzone at the University of Pennsylvania, 215-349-8141. Thank you very much for your valuable participation in this research.

Sean Bouvrette Project Manager Women's Health Study University of Michigan

TOD	AY'S DATE				ID				
			INTERIM QUES	TIONNAIRE - U					
		<b>GENE</b>	TIC TEST	ING-SECT	<u>ION 1</u>				
1.	Have you cor project?	ntributed a blo	od or tissue sample	to the <b>GENETIC</b>	TESTING portion of the	e research			
	□ Yes □ No								
2.	Has any member of your family contributed a blood or tissue sample to the <u>GENETIC TEST</u> portion of the research project?								
	r	<b>p</b> oj-		No 🗆 I Don't F	ζnow	B22.			
3.	Have you or a	ny family me	mbers received not	ification that genetic	c results are available?	B23.			
	1	here Has Been No otification	Results Are Available	Results Are NOT YET Available	Results will NEVER BE Available, I am Not Eligible				
4.	Have you recount Yes	When did th  What was th  □ University	o (Skip to Question is occur?  The source of this inf	ormation?	mo/yr)				
5.	Has <b>any fam</b> i □ Yes		eceived results of a to (Skip to Next Se		oreast or ovarian cancer o't Know (Skip to Next				
	5a.	When did th	is occur?	(r	no/yr)				
	5b.		e source of this inf y of Pennsylvania	ormation?	Testing □Other:				
	5c.	What were the	he results? (Option:	al)					
	5d.	able to figure	e out whether you a or breast cancer wi	ults from your relatere positive or negath this information?   Don't Known		you been nveys			

## **PERSONAL ATTITUDES SECTION**

1. For each of these statements, please indicate the extent to which you agree or disagree by circling the appropriate number. There are no right or wrong answers. We are only interested in your opinions.

		Strong Disag				trongly Agree	
a.	If you don't have your health, you don't have anything.	1	2	3	4	5	L5a.
b.	There are many things I care about more than my health.	1	2	3	4	5	L5b.
c.	Good health is of only minor importance in a happy life.	1	2	3	4	5	L5c.
d.	There is nothing more important than good health.	1	2	3	4	5	L5d.
e.	In uncertain times, I usually expect the best.	1	2	3	4	5	E1.
f.	It's easy for me to relax.	1	2	3	4	5	E2.
g.	If something can go wrong for me, it will.	1	2	3	4	5	E3.
h.	I always look on the bright side of things.	1	2	3	4	5	E4.
i.	I'm always optimistic about my future.	1	2	3	4	5	E5.
j	I enjoy my friends a lot.	1	2	3	4	5	E6.
k.	It's important for me to keep busy.	1	2	3	4	5	E7.
1.	I hardly ever expect things to go my way.	1	2	3	4	5	E8.
m.	Things never work out the way I want them to.	1	2	3	4	5	E9.
n.	I don't get upset too easily.	1	2	3	4	5	E10.
0.	I'm a believer in the idea that "every cloud has a silver lining."	1	2	3	4	5	E11.
p.	I rarely count on good things happening to me.	1	2	3	4	5	E12.

## **GENETIC TESTING-SECTION 2**

1.	risk fo you co	dical test may so or developing a to onsider taking the se check one	form of breast a us genetic test?	ınd ovarian can	ne women to leacer that runs in	arn their genetic families. Would	B15.
	(1)	I will <u>c</u>	<u>lefinitely</u> take t	he test <u>immedia</u>	tely when it bed	comes available.	
	(2)	I will <u>c</u>	<u>lefinitely</u> take t	he test, but I am	not sure if imr	nediately.	
	(3)	I will <u>ş</u>	orobably take th	e test immediat	ely when it bec	omes available.	
	(4)	I will I	orobably take th	ne test, but not i	mmediately.		
	(5)	I am <u>u</u>	ndecided wheth	er I will take th	e test		
	(6)	I will I	orobably not tal	ce the test.			
	(7)	I will <u>c</u>	lefinitely not ta	ke the test.			
2.	On the you m	e following scale ay be at increas	e, indicate how ed risk for brea	distressing it is st cancer becau	for you to kno se of your fami	ow that ly history?	B66.
		Distressing			T	Distressing	
		1	2	3	4	5	
3.	How d	listressing it is t ered gene associ	o be given the clated with incre	opportunity to based risk for bro	be tested for the east cancer?	BRCA-1 gene,	В67.
		Not At All Distressing				Very Distressing	
		1	2	3	4	5	
4.	How d	listressed do you before you rece	u expect to be ive results)?	when you actua	lly get tested fo	or the BRCA-1	B68.
		Not At All Distressed				Very Distressed	
		1	2	3	4	5	
5.	How d BRCA	listressed would -1 gene?	I you be if you	took the test an	d found that yo	u <b>had</b> the	В69.
		Not At All Distressed				Very Distressed	
		1	2	3	4	5	

	Not At All Distressed						Very Distresse	:d
	1	2	3		4		5	
Overa gene?	ll, to what exten	t do you welcon	ne the op	portuni	ty to be	tested f	or the BRC	<b>A-</b> 1
	Not At All						Very Much So	
	1	2	3		4		5	
			Not A	t All		All Th	e Time	
						-		
	often do you wo		Not A	t All	3	All Th	e Time	
develo To wh		cer? se worries	1	1	3	1	Т —	
To whinterfe	ping breast cand at extent do the	se worries ery day life? rry about	1	2		4	5	

(-8)  $\square$  This question does not apply because of surgery.

How many times have you conducted a breast self-examinations (BSE) in the past six months?

\_times

B33.

13.

14.	How	confident are	you tha	at you will	perform	n breast s	elf exami	ination (BSE)		
	14a.	as f <b>reque</b>	ently as	needed?	(-8)	Does No	t Apply	Because of Sur	rgery	B34a.
		Not at All	2	3	4	5	6 V	ery Much So 7		
	14b.	as carefu	illy an	d compet	• -	_		oly Because of	f Surgery	B34b.
		Not at All	2.	3	4	5	۱ 6	Very Much So		

For each of the following areas of your life, you will be asked to make <u>two</u> ratings. First, indicate how much these decisions have been affected by <u>the possibility that you have an increased risk for breast cancer</u> (based on your family history). Second, how much would these decisions be affected by <u>the results of genetic testing</u>?

1 2 3 4 5
Not at all affected Very much affected

		<u>Have</u> <u>at</u>	e been risk f	affecte or bred					affect f genet			
15.	Decisions about having children	1	2	3	4	5	1	2	3	4	5	B35a B35b
16.	Decisions about form of birth control	1	2	3	4	5	1	2	3	4	5	B36a B36b
17.	Decisions about which steps to take to prevent the recurrence of breast cancer	1	2	3	4	5	1	2	3	4	5	B37a B37b
18.	Decisions about work and career	1	2	3	4	5	1	2	3	4	5	B38a B38b
19.	Decisions about savings and financial planning	1	2	3	4	5	1	2	3	4	5	B39a B39b
20.	Decisions about plans for the future	1	2	3	4	5	1	2	3	4	5	B40a B40b

21.	Answer	the	following	auestion	only	if	vou	have	(biological)	daughters.
	And the second second									

☐ Does Not Apply (Skip to Question 22)

B41.

		Have been affected by being at high risk for breast cancer				Would be affected by the results of genetic testing					
a. Plans for your daughter's future	1	2	3	4	5	1	2	3	4	5	B42

22. Do you feel you have enough information about breast cancer to make any decisions that might be necessary?

Not At All						Very Much
1	2	3	4	5	6	7

B43.

23. Do you feel you are adequately informed about the benefits and drawbacks of genetic testing for risk of breast cancer?

Not At	Not At							
All	All							
1	2	3	4	5	6	7		

B44.

24. Do you feel you are adequately informed about what you could do to reduce your risk of breast cancer if you had the altered BRCA1 gene?

Not At All						Very Much
1	2	3	4	5	6	7

B45.

25. Do you feel you are adequately informed about the benefits and drawbacks of each option available to women who have the altered BRCA1 gene?

Not At All			Very Much	B46.			
1	2	3	4	- 5	6	7	

26.	Do you feel you are adequately informed about what it would mean for your children if you had the altered BRCA1 gene?
	· · ·

Not At All						Very Much
1	2	3	4	5	6	7

B47.

#### 27. How confident are you that you:

a. Will make the best decision in deciding whether to be tested for BRCA1, the altered gene associated with risk of breast cancer?

Not At All							B48a.
1	2	3	4	5	6	7	

b. Would cope effectively with a finding that you had the altered BRCA1 gene?

Not At All						Very Much	В48Ь.
1	2	3	4	5	6	7	

c. Would make the best decision concerning your options if you were found to have the altered BRCA1 gene?

Not At All					, , , , , ,	Very Much	B48c.
1	2	3	4	5	6	7	

d. Would be able to follow through and cope effectively over the long haul if you were found to have the altered BRCA1 gene?

Not At All						Very Much	B48d.
1	2	3	4	5	6	7	

## **RELATIONSHIPS SECTION**

1.		ere anyone in your lout holding back?	ife with who	m you can	share y	your mo	st private feelings	C21.
	WILL	out noiding ouex.	(1) Tes	(5) 🗆 No				
2.		arried, can you sharing back?	e your most j	private feeli	ngs w	ith your	husband without	C21a.
			(1) $\square$ Yes	(5) No				
3.		arried, is there anyo most private feeling			?	whom y	you can share	С21ь.
1.		any of the following All That Ap				,		D1(a-m)
a.		You retired, wer from work.	e fired, or lai	d off	g.		A close family membe ill or injured.	r was seriously
b.		You were unempy work.	ployed and lo	oking for	h.		You had a marital sepa divorce.	ration or
c.		Your spouse retail laid off from wo		d, or	i.		You had serious troubl or close friends.	es with relative
d		Your spouse wa looking for world	s unemploye k.	d and	j.		Your spouse had troub difficulties with relative	
e.		You had problem court.	ns with the p	olice or	k.		friends.  A close family member	r died.
f.		You got into seri difficulties.	ous financial		l. m.		A close friend or relative You were seriously ill	

## **MARRIAGE SECTION**

The following questions apply to persons who are married or living with a partner. If you are not married or living with a partner, check the appropriate box and please skip to the Next Section, MOOD.

Not married or living with a partner  $\Box$ 

Most persons have disagreements in their relationships. Please check the appropriate box to indicate the extent of agreement or disagreement experienced between you and your partner **DURING THE PAST MONTH**, regarding.

<b>F</b>		Always Agree	Almost Always Agree	Occa- sionally Disagree	Fre- quently Disagree	Almost Always Disagree	Always Disagree
1.	Religious matters	6	5	4	3	2	1
2.	Demonstration of affection	6	5	4	3	2	1
3.	Sex relations	6	5	4	3	2	1
4.	Conventionality (correct or proper behavior)	6	5	4	3	2	1
5.	Making major decisions	6	5	4	3	2	1
6.	Career decisions	6	5	4	3	2	1

		All of the time	Most of the time	More often than most	Occa- sionally	Rarely	Never	
7.	How often do you discuss or have you considered divorce, separation, or terminating your relationship?	1	2	3	4	5	6	H16
8.	Do you ever regret that you married (or are living together)?	1	2	3	4	5	6	H20
9.	How often do you and your husband/partner quarrel?	1	2	3	4	5	6	H21
10.	How often do you and your husband/partner "get on each other's nerves?"	1	2	3	4	5	6	H22

H3.

E-a.

H4.

H6.

H7.

H12.

H15.

	All of	Most of	Some of	Very few	None of
	Them	Them	Them	of Them	Them
11. Do you and your husband/partner engage in outside interests together?	5	4	3	2	1

H24.

How often would you say the following events occur between you and your husband/partner?

		Never	Less than once a month	About twice a month	About twice a week	Once a day	More Often
12.	Have a stimulating exchange of ideas	1	2	3	4	5	6
13.	Calmly discuss something	1	2	3	4	5	6
14.	Work together on a project	1	2	3	4	5	6

H25.

H27.

H28.

15. Considering only the positive feelings you have toward your husband/partner, and ignoring the negative ones, please rate how positive these feelings are:

H33.

Not A Posit								Extremely Positive				
1	2	3	4	5	6	7	8	9	10			

16. Considering only the negative feelings you have toward your husband/partner, and ignoring the positive ones, please rate how negative these feelings are:

H34.

Not A Nega									Extremely Negative		
1	2	3	4	5	6	7	8	9	10		

17. The following questions concern your husband's involvement in your health care.

		Never	,			Very Often	
a.	How often does your husband/partner go with you to your appointments with doctors?	1	2	3	4	5	H35
b.	How often does your husband/partner talk with your doctor or other medical personnel about your risk for breast cancer?	1	2	3	4	5	Н35
÷.	How often does your husband/partner keep track of what you need to do about your risk for breast cancer?	1	2	3	4	5	Н35
<b>1</b> .	How often does your husband/partner change his activities to assist you in your health care?	1	2	3	4	5	Н35

18.	Has your l informed a	nusband/p about you	oartner att r risk for	ended ind breast car 1 Yes □	ncer an	l, family od what can  5  No	or gro n be o	up sessions to become done?	Н36.
19.	concerning	n contact g your ris	has your l k for brea	husband/p st cancer.	artner	had with 1	medio	cal personnel	Н37.
		r None 1	2	3	4	5	6	A lot 7	
20.	Do you fee cancer and	el your hu what car	isband/pa i be done	rtner is ad about it?	lequate	ely informe	ed co	ncerning your risk for breast	Н38.
	No	t at All	2	3	4	5	6	Very Much 7	
21.	To what exhealth care	ktent are	you satisf	ied with y	our hu	ısband/par	tner's	involvement in your	Н39.
	No	t at All	2	3	4	5	6	Very Much	

# **MOOD SECTION**

1.	blue,	e you <b>ever in your lifetime</b> had two weeks or more when nearly every day, or depressed <u>or in which you lost all interest in things like work or hobbied</u> ally liked to do for fun?	
	usuai	1 5  Solution 1 State of the St	I14
	1a.	If there was such a two-week period, did your work or relationships such a Yes   No	ffer? I14a.
	1b.	If there was such a two-week period, did you get counseling or psychotherapy?  1 5  ☐ Yes ☐ No	I14b.
	1c.	If there was such a two-week period, did you get medication for this condition?  1 5  ☐ Yes ☐ No	I14c.
2.	felt s	he past 6 months, have you had two weeks or more when nearly every days and, blue, or depressed or in which you lost all interest in things like work of bies or things you usually liked to do for fun?  1 5  Yes  No (Skip to Question 3)	ny you r I12.
	2a.	If there was such a two-week period in <b>the past 6 months</b> , did your work or relationships suffer?  1 5  Yes □ No	I12a.
	2b.	If there was such a two-week period in the past 6 months, did you go counseling or psychotherapy?  1 5  Yes  No	et I12b.
	2c.	If there was such a two-week period in <b>the past 6 months</b> , did you go medication for this condition?  1 5  □ Yes □ No	et I12c.
3.		you <b>currently</b> receiving counseling, psychotherapy or medication for depressional problems?  1 5  Yes  No	ession I13.

#### **STRAIN SECTION**

LISTED BELOW ARE SOME SYMPTOMS OF STRAIN THAT PEOPLE SOMETIMES HAVE. Please Read Each One Carefully And Check The Answer Which Best Reflects How Much That Symptom Has Bothered You During the <u>Past Three Months</u>.

		Not at all	<u>A little</u>	Ouite a bit	<u>Extremely</u>	
1.	Suddenly scared for no reason	1	2	3	4	K
2.	Feeling fearful	1	2	3	4	K
3.	Faintness, dizziness, or weakness	1	2	3	4	K
4.	Nervousness or shakiness inside	1	2	3	4	K
5.	Heart pounding or racing	1	2	3	4	K
5.	Trembling	1	2	3	4	K
7.	Feeling tense or keyed up	1	2	3	4	K
3.	Headaches	1	2	3	4	K
9.	Spells of terror or panic	1	2	3	4	K
10.	Feeling restless, can't sit still	1	2	3	4	<b>K</b> 1
11.	Feeling low in energyslowed down	1	2	3	4	K1
12.	Blaming yourself for things	1	2	3	4	<b>K</b> 1
13.	Crying easily	1	2	3	4	K1
14.	Loss of sexual interest or pleasure	1	2	3	4	<b>K</b> 1
15.	Poor appetite	1	2	3	4	K1
16.	Difficulty falling asleep, staying asleep	1	2	3	4	K1
17.	Feeling hopeless about the future	1	2	3	4	K1
18.	Feeling blue	1	2	3	4	K1
19.	Feeling lonely	1	2	3	4	K1
20.	Feeling trapped or caught	1	2	3	4	K2
21.	Worrying too much about things	1	2	3	4	К2
22.	Feeling no interest in things	1	2	3	4	K2
23.	Thoughts of ending your life	1	2	3	4	K2
24.	Feeling everything is an effort	1	2	3	4	K2
25.	Feelings of worthlessness	1	2	3	4	<b>K</b> 2

### **COPING SECTION**

1. Sometimes people can find unexpected benefits in difficulties. We are interested in the ways in which you might have made positive use of your risk for breast cancer. For each of the statements below, indicate the degree to which your life is affected <u>positively</u> by your risk of breast cancer.

		Not At All		A Small Degree	A Moderate Degree	A Great Degree	A Very Great Degree	
a.	My priorities about what is important in life.	1	2	3	4	5	6	L6a.
b.	I'm more likely to try to change things which need changing.	1	2	3	4	5	6	L6b.
c.	An appreciation for the value of my own life.	1	2	3	4	5	6	L6c.
d.	A feeling of self-reliance.	1	2	3	4	5	6	L6d.
e.	A better understanding of spiritual matters.	1	2	3	4	5	6	L6e.
f.	Knowing that I can count on people in times of troubles.	1	2	3	4	5	6	L6f.
g.	A sense of closeness with others.	1	2	3	4	5	6	L6g.
h.	Knowing I can handle difficulties.	1	2	3	4	5	6	L6h.
i	A willingness to express my emotions.	1	2	3	4	5	6	L6i.
j.	Being able to accept the way things work out.	1	2	3	4	5	6	L6j.
k.	Appreciating each day.	1	2	3	4	5	6	L6k.
1.	Having compassion for others.	1	2	3	4	5	6	L6l.
m.	I'm able to do better things with my life.	1	2	3	4	5	6	L6m.
n.	New opportunities are available which wouldn't have been otherwise.	1	2	3	4	5	6	L6n.

2. This set of questions deals with ways you've been coping with the stress in your life that comes with being at risk for breast cancer. There are many ways people try to deal with problems. Obviously, different people deal with things in different ways, but we are interested in how you've tried to deal with it. Each item says something about a particular way of coping. We 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 it seems to be working but just whether or not you're doing it. Use these response choices below and try not to let one answer influence another. Make your answers as true FOR YOU as you can.

		I haven't been doing this at all I	I've been doing this a little bit 2	I've been doing this some 3	I've been doing this a lot 4
a.	I've been turning to work or other activities to take my mind off things.	1	2	3	4
b.	I've been concentrating my efforts on doing something about my situation.	1	2	3	4
c.	I've been saying to myself "this isn't possible."	1	2	3	4
d.	I've been using alcohol or other drugs to make myself feel better.	1	2	3	4
e.	I've been getting emotional support from others.	1	2	3	4
f.	I've been giving up trying to deal with it.	1	2	3	4
g.	I've been taking action to try to make the situation better.	1	2	3	4
h.	I've been refusing to believe that it is possible that I have the gene.	1	2	3	4
i.	I've been saying things to let my unpleasant feelings escape.	1	2	3	4
•	I've been using alcohol or other drugs to help me get through it.	1	2	3	4
k.	I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4
١.	I've been trying to come up with a strategy about what to do.	1	2	3	4
m.	I've been getting comfort and understanding from someone.	1	2	3	4

	I haven't been doing this at all I	I've been doing this a little bit 2	I've been doing this some 3	I've been doing this a lot 4
. I've been giving up the attempt to cope.	1	2	3	4
I've been accepting the possibility that I might have the gene.	1	2	3	4
p. I've been expressing my negative feelings.	1	2	3	4
I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4
I've been learning to live with the possibility that I might have the gene.	1	2	3	4
s. I've been thinking hard about what steps to take.	1	2	3	4
t. I've been praying or meditating.	1	2	3	4
u. I've been making fun of the situation.	1	2	3	4

3. The following items are to be answered only by those women who are <u>married or living with a partner</u>.

□ Not married or living with a partner

(Skip to Last Section on page 15, Background Data)

		I haven't been doing this at all I	I've been doing this a little bit 2	I've been doing this some 3	I've been doing this a lot 4	
a.	I've been denying or hiding my anger around my husband/partner.	1	2	3	4	L8a.
b.	I've been denying or hiding my worries around my husband/partner.	1	2	3	4	L8b.
c.	I've been avoiding talking about my problems around my husband/partner.	1	2	3	4	L8c.
d.	I've acted more positive around my husband/partner than I feel.	1	2	3	4	L8d.

#### **BACKGROUND DATA**

These are a few questions about your religious background, that we forgot to ask on the original questionnaire.

1.	Religion	ı:	Catholic Jewish Muslim	(1)	Protestant Buddhist Other None	(4) ☐ (5) ☐ (6) ☐ (7) ☐	A3.
	1a.	How often do you (1) ☐ Less Often Ti	•	(5)	)	A Month or More	A3a.
	1b.	How important	are religious a	nd spiritual t	peliefs in your li	fe?	A3b.
		Not at All	2	3	Ver	ry Important 5	

Once Again, We thank you for all of your valued participation in this study.

		0	





# WOMEN'S HEALTH STUDY

Spouse/Partner Questionnaire

Today's Date	
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SPOP

# **BACKGROUND DATA SECTION**

1.	Date of Birth	Month	Day _	Year		A1.
2.	Ethnic Background:	White Hispanic Native American	☐ 1 ☐ 2 ☐ 3	Black Asian Other	<ul><li>□ 4</li><li>□ 5</li><li>□ 6</li></ul>	A2.
3.	Religion:	Catholic Jewish Muslim	□ 1 □ 2 □ 3	Protestant Buddhist Other None	<ul><li>□ 4</li><li>□ 5</li><li>□ 6</li><li>□ 7</li></ul>	A3.
		ou attend religious se Once a Month		ew Times A Mo	nth or More	A3a.
	3b. How important Not at All	are religious and spiri	itual beliefs 4	s in your life? Very Imp 5	oortant	A3b.
4.	Are you currently working	g for pay outside the	home? Y	es □ 1 N	o 🗆 5	A7.
5.	If <u>yes</u> , about how many	hours per week are yo	ou working	for pay?		A8.
		21-30 2) (3)		31-40 41 (4)	or more  (5)	
6.	What is the highest level of	f education you have	completed	? (Check one)		A9.
	<ul> <li>1 □ Less than 9th grade</li> <li>2 □ Dropped out of high s</li> <li>3 □ Completed high schoo</li> <li>4 □ Some college</li> </ul>		6 □ Sc		e professional training ite or professional trainir	ng
<b>The</b> Plea	e following two questions asse check the appropriate box	are optional, but we x. (Check one)	hope that	you will provi	de this information.	
7.	What is your household's t (1) ☐ Less than \$10,000 (2) ☐ \$10,000 to \$19,99 (3) ☐ \$20,000 to \$29,99	(4)	<b>c one)</b> 000 to \$39 000 to \$49 000 to \$59	,999 (8) $\square$		A10.
8.	How many people (adults a	nd children) does this	s income su	ipport?	_	A11.

### PERSONAL ATTITUDES SECTION

1. For each of these statements, please indicate the extent to which you agree or disagree by circling the appropriate number. There are no right or wrong answers. We are only interested in your opinions.

		Strong Disagi				rongly Agree	
a.	If you don't have your health, you don't have anything.	1	2	3	4	5	L5a.
b.	There are many things I care about more than my health.	1	2	3	4	5	L5b.
c.	Good health is of only minor importance in a happy life.	1	2	3	4	5	L5c.
d.	There is nothing more important than good health.	1	2	3	4	5	L5d.
e.	In uncertain times, I usually expect the best.	1	2	3	4	5	E1.
f.	It's easy for me to relax.	1	2	3	4	5	E2.
g.	If something can go wrong for me, it will.	1	2	3	4	5	E3.
h.	I always look on the bright side of things.	1	2	3	4	5	E4.
i.	I'm always optimistic about my future.	1	2	3	4	5	E5.
j.	I enjoy my friends a lot.	1	2	3	4	5	E6.
k.	It's important for me to keep busy.	1	2	3	4	5	E7.
1.	I hardly ever expect things to go my way.	1	2	3	4	5	E8.
m.	Things never work out the way I want them to.	1	2	3	4	5	E9.
n.	I don't get upset too easily.	1	2	3	4	5	E10.
0.	I'm a believer in the idea that "every cloud has a silver lining."	1	2	3	4	5	E11.
p.	I rarely count on good things happening to me.	1	2	3	4	5	E12.

#### **HEALTH SECTION**

The following questions concern your wife/partner's risk of developing breast cancer again and of her having the altered gene which has been found to be associated with increased risk for breast cancer. As you may know, breast cancer runs in certain families. In some of these families, persons who develop cancer have an altered version of a gene, BRCA1. Some family members will inherit the gene and others will not.

		Not At All				All The Time
1.	How often do you worry about your wife/partner again developing breast cancer?	1	2	3	4	5
2.	To what extent do these worries interfere with your every day life?	1	2	3	4	5
3.	How often do you worry about your wife/partner having the altered gene associated with risk for breast cancer?	1	2	3	4	5
4.	To what extent do worries about your wife/partner having this altered gene interfere with your every day life?	1	2	3	4	5
5.	How often do you worry about developing cancer yourself?	1	2	3	4	5

6. How likely do you think your wife/partner is to develop breast cancer again in **the near future**? **B9.** (Please circle one).

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

7. Overall, what do you believe your wife/partner's risk is of developing breast cancer again at some point in her lifetime?

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

B10.

B49.

8. Overall, what do you believe your wife/partner's risk is of developing some other cancer **unrelated** to breast cancer **at some point in her lifetime?**B14.

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

9. How often does your wife/partner express concern and seek support from you about the risk of breast cancer to herself and women in her family?

NeverRarelySometimesOften1234

10. How much of a burden is this on you?

B50.

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

11. How often do you discuss genetic testing for breast cancer with your wife/partner?

B51.

Never	Rarely	Sometimes	Often
1	2	3	4

12. When you have these discussions, who generally initiates them?

B52.

You	Your Wife/partner	Equally		
1	2	3		

13. How satisfied are you with these discussions?

B53.

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

14. How often do you and your wife/partner get into a disagreement or conflict over the issue of her getting genetic testing for the risk of breast cancer?

B54.

Never	Rarely	Sometimes	Often		
1	2	3	4		

15. Do you think it is beneficial to have genetic testing for risk of breast cancer available to women? B55.

Not At All	A Little	Somewhat	A Great Deal		
1	2	3	4		

16. Do you want your wife/partner to get genetic testing for risk of breast cancer?

B56.

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

17.				do you want your opinion to list ion whether to be tested for			B57.
			Not At All	A Little	Somewhat	A Great Deal	
			1	2	3	4	
18.						account in your or breast cancer	? <b>B58.</b>
			Not At All	A Little	Somewhat	A Great Deal	
			1	2	3	4	
19.	Overal for the	ll, how impo altered gen	ortant is your or the carrying susc	pinion in your veptibility to bre	wife/partner's deast cancer?	lecision whether	to be tested  B59.
			7,00 120 1211	2.000	Somownat	Deal	
			1	2	3	4	
19a.	Do you t	oelieve your	wife has the all	tered gene that  (1)  Yes	increases the ri	isk of breast canc	eer? <b>B60.</b>
19b.	How cor	nfident are y	ou in this belie	f?			
		Not At Al Confident				Very Confident	
		1	2 3	4	5	6 7	B61.
20.	Have y wife/pa	vou attended artner's risk	for breast cance	er and what car	n be done?	me informed abo	out your B62.
21.	Нош п	nich contact			NO	rning her risk of	202202
<b>~</b> 1.	110W II	Very Little	2 3	4 5		A Lot	cancer? B63.

22a.	Overall, do you feel you are adequately informed concerning your wife/partner's risk for cancer and what can be done about it?								B43a.
		Not at All	2	3	4	5	6	Very Much 7	
22b.	Do yo	u feel you a cancer <b>aga</b>		ately info	rmed abo	out your	wife/par	tner's risk for developing breast	B43b.
		Not at All	2	3	4	5	6	Very Much 7	
22c.	Do yo	u feel you ar testing for				out the b	enefits a	nd drawbacks of genetic	B44.
		Not at All	2	3	4	5	6	Very Much 7	
22d.	Do yo							fe/partner could do personally to BRCA1 gene?	B45.
		Not at All	2	3	4	5	6	Very Much 7	
22e.	Do yo	u feel you a options ava						nd drawbacks of CA1 gene?	B46.
		Not at All	2	3	4	5	6	Very Much 7	
22f.	Do yo	•	_	-		d gene		mean for your children if your eck here if you do not have	B47. children.
		Not at All	2	3	4	5		Very Much 7	C-22f
23.	How c	onfident are	you tha	at your wi	fe/partne	r:			
	23a.	Will make associated					be tested	l for BRCA1, the altered gene	B48a.
		Not at All	2	3	4	5	6	Very Much 7	
	23b.	Would cop	e effect	ively with	the findi	ng that	she had t	he altered BRCA1 gene?	B48b.
		Not at All	2	3	4	5	6	Very Much 7	

23c.	Would make the best decision concerning her options if she were found to have the altered BRCA1 gene?							
	Not at All					•	Very_Much	
	1	2	3	4	5	6	7	

Would be able to follow through with her decisions and cope effectively over the long haul if she were found to have the altered BRCA1 gene?

B48d.

(continued) How confident are you that your wife/partner:

23.

24. Please indicate the extent to which you agree or disagree with the following statements using the 1 (strongly disagree) to 5 (strongly agree) scale. Please try to provide your opinion for all of these questions. However, if you feel you simply do not know enough to have an opinion, check the "I don't know" box.

Strongly Strongly I Don't Disagree Agree Know B20a. Mammography is effective in the early detection of 2 3 4 1 5 breast cancer in women. B20b. b. Breast cancer that is detected early is curable. 1 2 3 4 5 9 B20c. Mammography can detect lumps that cannot be felt by 2 3 c. 1 4 5 9 a woman or by her doctor. B20d. d. If more women went for breast screening, there would 1 2 3 4 5 be fewer deaths from breast cancer. If a lump is found in a woman's breast, it is usually e. 1 2 3 4 5 9 B20f. too late to do anything about it. f. There are so many things that could happen to 1 2 3 9 4 5 B20i. someone's health that it is pointless for a woman to worry about breast cancer. If a woman were found to have breast cancer, the 1 2 3 4 5 9 g. B20m. chances of it being cured are high. h. Once a woman has had effective treatment for breast 1 2 9 3 4 5 B20n. cancer, she will not get it again. i. A mastectomy totally eliminates a woman's risk for 1 2 3 4 5 9 B200. breast cancer. j. All women who have the altered version of the 2 1 3 4 5 9 B20p. BRCA1 gene will get breast cancer. k. Most of the breast cancer in the United States is due to 1 2 3 4 9 5 altered versions of the BRCA1 gene. B20q.

Strongly Disagree					St A	I Don't Know	
1.	The next decade is going to bring major advances in the detection and treatment of breast cancer.	1	2	3	4	5	9
m.	Over the next decade, medical break- through's are going to make breast cancer much less of a threat to women's health.	1	2	3	4	5	9

B20r.

B20s.

If your wife/partner were to take the test and find that she <u>did not</u> have the altered version of the BRCA1 gene which is associated with high risk for breast cancer, what would you expect your reactions to be? 25.

		Strong Disagr				rongly Agree		
a.	I would feel wonderful.	1	2	3	4	5	B18a.	
b.	I would feel I had been told what I knew all along.	1	2	3	4	5	B18b.	
c.	I would feel relieved.	1	2	3	4	5	B18c.	
d.	I would not believe the results.	1	2	3	4	5	B18d.	
e.	I would fall apart emotionally.	1	2	3	4	5	B18e.	
f.	I would feel guilty.	1	2	3	4	5	B18f.	
g.	I would still feel anxious.	1	2	3	4	5	B18g.	
h.	I would feel angry.	1	2	3	4	5	B18h.	
i.	I would feel prepared for the future.	1	2	3	4	5	B18i.	
j.	I would feel I had done all I needed to do.	1	2	3	4	5	B18j.	
k.	I would not feel very differently.	1	2	3	4	5	B18k.	

If your wife/partner were to take the test and find out that she <u>had</u> the altered version of the BRCA1 gene for breast cancer, what would you expect yo<u>ur reactions to be?</u> 26.

		Strong Disagi	gly ree			rongly Igree		
a.	I would feel relieved about being more certain.	1	2	3	4	5	B19	
b.	I would feel I had been told what I knew all along.	1	2	3	4	5	B19	
c.	I would not believe the results.	1	2	3	4	5	B19	
d.	I would feel guilty.	1	2	3	4	5	B19	
e.	I would feel depressed.	1	2	3	4	5	B19	

9a.

9b.

9c.

9d.

9e.

		Strong Disagr			St	rongly Agree		
f.	I would feel worried about the future.	1	2	3	4	5	B19f.	
g	I would fall apart emotionally.	1	2	3	4	5	B19g.	
h.	I would feel anxious.	1	2	3	4	5	B19h.	
i.	I would feel angry.	1	2	3	4	5	B19i.	
j.	I would not feel very differently.	1	2	3	4	5	B19j.	
k.	I would want my daughters to be tested as soon as possible.	1	2	3	4	5	B19k.	

27. The following questions concern your involvement in your wife/partner's health care:

		Not at All					
a.	To what extent do you go with your wife/partner to her appointments with doctors?	1	2	3	4	5	H35a.
b.	To what extent do you talk with your wife/partner's doctor or other medical personnel about her risk of cancer?	1	2	3	4	5	Н35Ь.
c.	To what extent do you keep track of what your wife/partner needs to do about her risk of cancer?	1	2	3	4	5	Н35с.
d.	To what extent do you change your activities to look after your wife/partner?	1	2	3	4	5	H35d.

28. If my wife/partner were tested and found to have the altered BRCA1 gene carrying increased risk of breast cancer, I would want her to manage her risk by relying:

a. Being extra careful about breast self-examination and regular medical examinations.

B64a.

Not at						Very
All						Much So
1	2	3	4	5	6	7

b. Getting preventive surgery.

B64b.

Not at	:					Very
All						Much So
1	2	3	4	5	6	7

29. I do not believe it would be my place to tell my wife/partner my opinion about what do about her risk of breast cancer.	she should
---	------------

Strongly Disagree						Strongly Agree
1	2	3	4	5	6	7

B65.

#### **RELATIONSHIPS**

		<u>KELATIO</u>	INDII	<u> </u>	<u>3</u>	
1.		there anyone in your life with whom you can shar ithout holding back?	e your i	most	private feelings	C21.
		$(1) \square \mathbf{Yes} \qquad (5) \square \mathbf{No}$				
2.	Ca	n you share your most private feelings with your	wife/pa	rtner	without holding back?	C21a.
		(1) $\square$ Yes (5) $\square$ No				
3.		there anyone besides your wife/partner with whore thout holding back?	n you c	an sh	nare your most private feelings	C21b.
4.		(1) ☐ Yes (5) ☐ No  we any of the events listed below happened to you heck All That Apply)	ı in <u>the</u>	past	six months?	D1 (a-m)
a.		You retired or were fired or laid off from work.	g.		A close family member was seriously ill or injured.	
b.		You were unemployed and looking for work.	h.		You had a marital separation or divorce.	
c.		Your spouse retired or was fired or laid off from work.	i.		You had serious troubles with relatives or close friends.	
d		Your spouse was unemployed and looking for work.	j.		Your spouse had troubles with relatives or close	
e.		You had problems with the	1-		friends.	
f.		police or court. You got into serious financial	k. l.		A close family member died.  A close friend or relative died.	
••		difficulties.	m.		You were seriously ill or injured.	

### **MARRIAGE SECTION**

Most people have disagreements in their relationships. Please indicate, using check marks the extent of agreement or disagreement experienced between you and your wife/partner on the following issues **DURING THE PAST MONTH**.

		Always Agree	Almost Always Agree	Occa- sionally Disagree	Fre- quently Disagree	Almost Always Disagree	Always Disagree	
1.	Handling family finances	1	2	3	4	5	6	Н1.
2.	Matters of recreation	1	2	3	4	5	6	Н2.
3.	Religious matters	1	2	3	4	5	6	Н3.
4.	Demonstration of affection	1	2	3	4	5	6	Н4.
5.	Friends	1	2	3	4	5	6	Н5.
6.	Sex relations	1	2	3	4	5	6	Н6.
7.	Conventionality (correct or proper behavior)	1	2	3	4	5	6	Н7.
8.	Philosophy of life	1	2	3	4	5	6	Н8.
9.	Ways of dealing with parents or in-laws	1	2	3	4	5	6	Н9.
10.	Aims, goals, and things believed important	1	2	3	4	5	6	H10.
11.	Amount of time spent together	1	2	3	4	5	6	H11.
12.		1	2	3	4	5	6	H12.
13.	Household tasks	1	2	3	4	5	6	Н13.
14.	Leisure time interests and activities	1	2	3	4	5	6	Н14.
15.	Career decisions	1	2	3	4	5	6	H15.

		All of the Time	Most of the Time	More Often than Most	Occa- sionally	Rarely	Never	
16.	How often do you discuss or have you considered divorce, separation, or terminating your relationship?	1	2	3	4	5	6	H16.
17.	How often do you or your wife/partner leave the house after a fight?	1	2	3	4	5 .	6	H17.
18.	In general, how often do you think that things between you and your wife/partner are going well?	1	2	3	4	5	6	H18.
19.	Do you confide in your wife/partner?	1	2	3	4	5	6	H19.
20.	Do you ever regret that you married (or lived together)?	1	2	3	4	5	6	H20.
21.	How often do you and your wife/partner quarrel?	1	2	3	4	5	6	H21.
22.	How often do you and your wife/partner "get on each other's nerves?"	1	2	3	4	5	6	H22.

	Every Day	Almost	Occa-	Danah	<b>N</b> /	
	Day	Every Day	sionally	Rarely	Never	
23. Do you kiss your						
wife/partner?	1	2	3	4	5	H23.

		All of Them	Most of Them	Some of Them	Very few of Them	None of Them	
wife	you and your /partner engage in ide interests together?	1	2	3	4	5	Н

H24.

How often would you say the following events occur between you and your wife/partner? Less than About About once a twice a twice a Once a More Never month month week day Often Have a stimulating exchange 25. 1 2 3 4 5 6 of ideas H25. 1 2 5 3 4 6 26. Laugh together H26. 1 2 3 4 5 6 27. Calmly discuss something H27. 2 1 3 4 5 6 28. Work together on a project H28. These are some things couples sometimes agree and sometimes disagree upon. Indicate if either item below caused differences of opinions or were problems in your relationship during the past month. (Check yes or no). 29. Being too tired for sex.  $(1) \square Yes$ (5) No H29. 30. Not showing love.  $(1) \square Yes$ (5) No H30. 31. The following scale represents different degrees of happiness in your relationship. The middle point "happy" represents the degree of happiness of most relationships. Please circle the number which best describes the degree of happiness, all things considered, of your relationship. H31. Extremely Fairly A Little Very Extremely Unhappy Unhappy Unhappy Happy Happy Happy Perfect 1 2 3 4 5 7 6 32. Please check one of the following statements to best describe how you feel H32. about the future of your relationship. (1).\_\_\_I want desperately for my relationship to succeed, and would go to almost any length to see that it does. (2).\_\_\_I want very much for my relationship to succeed, and will do all I can to see that it does. (3).\_\_\_I want very much for my relationship to succeed, and will do my fair share to see that it does. It would be very nice if my relationship succeeded, but I can't do much more than I am doing now to help it succeed. It would be nice if it succeeded, but I refuse to do any more

than I am doing now to keep the relationship going.

can do to keep the relationship going.

(6). My relationship can never succeed, and there is no more that I

33. Considering only the positive feelings you have toward your wife/partner, and ignoring the negative ones, please rate how positive these feelings are:

H33.

Not At All Positive									Extremely Positive	
1	2	3	4	5	6	7	8	9	10	

34. Considering **only the negative feelings** you have toward your wife/partner, and **ignoring the positive ones**, please rate how negative these feelings are:

H34.

Not At All							Extremely		
Negative							Negative		
1	2	3	4	5	6	7	8	9	10

#### **CURRENT FAMILY SECTION**

Please indicate the extent to which each of the following items describes your current family (your household).

		Strong Disag	gly ree			trongly Agree	,
1.	Planning family activities is difficult because we misunderstand each other.	1	2	3	4	5	M1.
2.	In times of crisis we can turn to each other for support.	1	2	3	4	5	M2.
3.	We cannot talk to each other about the sadness we feel.	1	2	3	4	5	М3.
4.	Individuals are accepted for who they are.	1	2	3	4	5	M4.
5.	We avoid discussing our fears and concerns.	1	2	3	4	5	М5.
6.	We can express feelings to each other.	1	2	3	4	5	M6.
7.	There are lots of bad feelings in the family.	1	2	3	4	5	М7.
8.	We feel accepted for who we are.	1	2	3	4	5	М8.
9.	Making decisions is a problem for our family.	1	2	3	4	5	М9.
10.	We are able to make decisions about how to solve problems.	1	2	3	4	5	M10.
11.	We don't get along well together.	1	2	3	4	5	M11.
12.	We confide in each other.	1	2	3	4	5	M12.

## YOUR HEALTH AND MOOD SECTION

1.	In general, would you say your health is:							
	(1)	Excellent	(2) U	ery Good	(3) □ Good	(4) 🗆 Fair	(5)	
2.	you f	elt sad, blue,	or depress		eks or more when neach you lost all interest do for fun?		I14.	
		(1)	□ Yes	(5) No (S	skip to Question 3)			
	2a.	If there was	is such a t	wo-week peri	od, did your work or	relationships	I14a.	
		(1)	□ Yes	(5) 🗆 No				
	2b.	If there was		wo-week peri	od, did you get couns	eling or	I14b.	
		(1)	□ Yes	(5) 🗆 N o				
	2c.	If there we condition?	as such a t	wo-week per	iod, did you get medi	cation for this	I14c.	
		(1)	□ Yes	(5) 🗆 N o				
3.	you fe	elt sad, blue,	or depress		weeks or more when th you lost all interest do for fun?		I12.	
		(1)	□ Yes	(5) \( \sum \) No (S	kip to Question 4)			
	3a.	If there was			riod (in the past 6 n	nonths), did your wo	ork <b>I12a.</b>	
		(1)	□ Yes	(5) 🗆 N o				
	3b.	If there was			riod (in the past 6 n	nonths), did you get	I12b.	
		(1)	□ Yes	(5) \( \sum \) N o				
	3c.	If there wa			riod, (in the past 6 i	months) did you get	I12c.	
		(1)	□ Yes	(5) 🗆 N o				
4.		ou <b>currently</b> ssion or emo			psychotherapy, or me	edication for	I13.	
		(1)	□ Yes	(5) □ N o				

#### **SYMPTOMS OF STRAIN SECTION**

LISTED BELOW ARE SOME SYMPTOMS OF STRAIN THAT PEOPLE SOMETIMES HAVE. Please Read Each One Carefully And Check The Answer Which Best Reflects How Much That Symptom Has Bothered You During the <u>Past Three Months</u>.

		1	2	3	4	
	<del></del>	Not at all	<u>A little</u>	<u>Quite a bit</u>	<u>Extremely</u>	
1.	Suddenly scared for no reason	1	2	3	4	K
2.	Feeling fearful	1	2	3	4	К
3.	Faintness, dizziness, or weakness	1	2	3	4	K
4.	Nervousness or shakiness inside	1	2	3	4	K
5.	Heart pounding or racing	1	2	3	4	К
6.	Trembling	1	2	3	4	К
7.	Feeling tense or keyed up	1	2	3	4	К
8.	Headaches	1	2	3	4	К
9.	Spells of terror or panic	1	2	3	4	K
10.	Feeling restless, can't sit still	1	2	3	4	<b>K</b> 1
11.	Feeling low in energyslowed down	1	2	3	4	K
12.	Blaming yourself for things	1	2	3	4	K
13.	Crying easily	1	2	3	4	K
14.	Loss of sexual interest or pleasure	1	2	3	4	K
15.	Poor appetite	1	2	3	4	<b>K</b> :
16.	Difficulty falling asleep, staying asleep	1	2	3	4	<b>K</b> :
17.	Feeling hopeless about the future	1	2	3	4	<b>K</b> :
18.	Feeling blue	1	2	3	4	<b>K</b> :
19.	Feeling lonely	1	2	3	4	K
20.	Feeling trapped or caught	1	2	3	4	K2
21.	Worrying too much about things	1	2	3	4	K:
22.	Feeling no interest in things	1	2	3	4	K2
23.	Thoughts of ending your life	1	2	3	4	K
24.	Feeling everything is an effort	1	2	3	4	K
25.	Feelings of worthlessness	1	2	3	4	K

#### **COPING SECTION**

1. Imagine that you are afraid of the dentist and have to get some dental work done. Which of the following would you do? Please answer **yes** or **no** for each choice.

		YES	NO	
a.	I would ask the dentist exactly what s/he was going to do.	1	5	L
b.	I would take a tranquilizer or have a drink before going.	1	5	L
c.	I would try to think about pleasant memories.	1	5	L
d.	I would want the dentist to tell me when I would feel pain.	1	5	L
e.	I would try to sleep.	1	5	L
f.	I would watch all the dentist's movements and listen for the sound of the drill.	1	5	L
g.	I would watch the flow of water from my mouth to see if it contained blood.	1	5	L
h.	I would do mental puzzles in my mind.	1	5	L

2. Imagine that you are being held hostage by a group of armed terrorists in a public building. Which of the following would you do?

		YES	NO	
a.	I would sit by myself and have as many daydreams and fantasies as I could.	1	5	L2_1
b.	I would stay alert and try to keep myself from falling asleep.	1	5	L2_2
c.	I would exchange life stories with the other hostages.	1	5	L2_3
d.	If there was a radio present, I would stay near it and listen to the bulletins about what the police were doing.	1	5	L2_4
e.	I would watch every movement of my captors and keep an eye on their weapons.	1	5	L2_5
f.	I would try to sleep as much as possible.	1	5	L2_6
g.	I would think about how nice it's going to be when I get home.	1	5	L2_7
h.	I would make sure I knew where every possible exit was.	1	5	L2_8

3. Imagine that due to a large drop in sales, it is rumored that several people in your department at work will be laid off. Your supervisor has turned in an evaluation of your work for the past year. The decision about lay-off has been made and will be announced in several days. Please answer yes or no for each choice.

		YES	NO	
a.	I would talk to my fellow workers to see if they knew anything about what the supervisor's evaluation of me said.	1	5	L3_1
b.	I would review the list of duties for my present job and try to figure out if I had fulfilled them all.	1	5	L3_2
c.	I would go to the movies to take my mind off things.	1	5	L3_3
d.	I would try to remember any arguments or disagreements I might have had with the supervisor that would have lowered his opinion of me.	1	5	L3_4
e.	I would push all thoughts of being laid off out of my mind.	1	5	L3_5
f.	I would tell my spouse that I'd rather not discuss my chances of being laid off.	1	5	L3_6
g.	I would try to think which employees in my department the supervisor might have thought had done the worst job.	1	5	L3_7
h.	I would continue doing my work as if nothing special was happening.	1	5	L3_8

4. Imagine that you are on an airplane, 30 minutes from your destination, when the plane unexpectedly goes into a deep dive and then suddenly levels off. After a short time, the pilot announces that nothing is wrong, although the rest of the ride may be rough. You, however, are not convinced that all is well. Please answer **yes** or **no** for each choice.

		YES	NO	
a.	I would carefully read the information provided about safety features in the plane and make sure I knew where the emergency exits were.	1	5	L4_1
b.	I would make small talk with the passenger beside me.	1	5	L4_2
c.	I would watch the end of the movie, even if I had seen it before.	1	5	L4_3
d.	I would call for the flight attendant and ask her/him exactly what the problem was.	1	5	L4_4
e.	I would order a drink or tranquilizer from the stewardess.	1	5	L4_5
f.	I would listen carefully to the engines for unusual noises and would watch the crew to see if their behavior was out of the ordinary.	1	5	L4_6
g.	I would talk to the passenger beside me about what might be wrong.	1	5	L4_7
h.	I would settle down and read a book or magazine or write a letter.	1	5	L4_8

5. This set of questions deals with ways you've been coping with the stress in your life that goes with your wife/partner possibly having the altered BRCA1 gene associated with risk for breast cancer. Obviously, different people deal with this stress in different ways, but we are interested in how you've tried to deal with it. Each item says something about a particular way of coping. We 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 it seems to be working, but just whether or not you're doing it. Use these response choices below and try not to let one answer influence another. Make your answers as true FOR YOU as you can.

		I haven't been doing this at all 1	I've been doing this a little bit 2	I've been doing this some 3	I've been doing this a lot 4
a.	I've been turning to work or other activities to take my mind off things.	1	2	3	4
b.	I've been concentrating my efforts on doing something about her situation.	1	2	3	4
c.	I've been saying to myself "this isn't possible."	1	2	3	4
d.	I've been using alcohol or other drugs to make myself feel better.	1	2	3	4
e.	I've been getting emotional support from others.	1	2	3	4
f.	I've been giving up trying to deal with it.	1	2	3	4
g.	I've been taking action to try to make the situation better.	1	2	3	4
h.	I've been refusing to believe that it is possible she has the gene.	1	2	3	4
i.	I've been saying things to let my unpleasant feelings escape.	1	2	3	4
j.	I've been using alcohol or other drugs to help me get through it.	1	2	3	4
ζ.	I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4
1.	I've been trying to come up with a strategy for what to do.	1	2	3	4

		I haven't been doing this at all I	I've been doing this a little bit 2	I've been doing this some	I've been doing this a lot 4
m.	I've been getting comfort and understanding from someone.	1	2	3	4
1.	I've been giving up the attempt to cope.	1	2	3	4
•	I've been accepting the possibility that she might have the gene.	1	2	3	4
•	I've been expressing my negative feelings.	1	2	3	4
•	I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4
•	I've been learning to live with the possibility she might have the gene.	1	2	3	4
	I've been thinking hard about what steps to take.	1	2	3	4
	I've been praying or meditating.	1	2	3	4
	I've been making fun of the situation.	1	2	3	4
•	I've been giving pep talks and encouraging my wife/partner.	1	2	3	4
٧.	I've been denying or hiding my anger around my wife/partner.	1	2	3	4
•	I've been denying or hiding my own worries around my wife/partner.	1	2	3	4
•	I've been trying to give my wife/partner opportunities to talk about her worries.	1	2	3	4
	I've been trying to find out what my wife/partner is feeling.	1	2	3	4
a.	I've been avoiding talking about my own problems around my wife/partner.	1	2	3	4
b.	I've acted more positive around my wife/partner than I feel.	1	2	3	4

The canc		ing questio	ns con	cern co	ping w	rith you	ır wife	/partner	's diagnosis a	and treatmer	nt for
6.	At your worst, how distressed did you feel about your wife/partner's diagnosis and treatment of cancer?										L8.
		Not at All	2	3	4	5	6	Very Mu 7	ach		
7.	blue,		or in wh	ich you l	lost all ir				every day you f or hobbies or	elt sad,	
				(1)	Yes	(5) \( \sum \) \( \sum \)	lo (Skip	to Ques	tion 8)		L9.
	a.	If there was	s such a		ek period Yes	l, <b>did y</b> oi (5) □ ]		or relation	onships suffer?		L9a.
	b.	If there was			ek period Yes	, did you (5) □ ]	-	unseling (	or		L9b.
	c.	If there w	as such		eek perio	-	_	nedication	n for this proble	em?	L9c.
8.	For each of the statements on the following page, indicate the degree to which this change occurred in you life as a result of your wife/partner being diagnosed and treated for breast cancer. Please use the following scale:										in your
	1 =	I experienced	no char	ige as a i	result of	my wife	e/partner	r's being o	diagnosed and to	reated for canc	er.
	2 =	I experienced and treated for			a <u>very sı</u>	nall deg	gree as a	a result of	f my wife/partn	er's being diag	gnosed
	3 =	I experienced and treated fo			small d	legree a	s a resul	lt of my v	wife/partner's be	eing diagnosed	I
	4 =	I experienced and treated for			moder:	ate degr	ee as a	result of 1	my wife/partner	r's being diagn	osed
	5 =	I experienced and treated for			great d	egree as	s a resul	t of my w	vife/partner's be	ing diagnosed	
	6 =	I experienced and treated for			ı <u>very gı</u>	reat deg	ree as a	result of	my wife/partne	er's being diag	nosed
	es not	apply because	I was no	ot with n	ny wife/	partner v	when sh	e was bei	ng treated for b	reast cancer.	L6.

		No Change	Very Small Degree	Small Degree	Moderate Degree	Great Degree	Very Great Degree	
a.	My priorities about what is important in life.	1	2	3	4	5	6	L6_a.
b.	I'm more likely to try to change things which need changing.	1	2	3	4	5	6	L6_b.
c.	An appreciation for the value of my own life.	1	2	3	4	5	6	L6_c.
d.	A feeling of self-reliance.	1	2	3	4	5	6	L6_d.
e.	A better understanding of spiritual matters.	1	2	3	4	5	6	L6_e.
f.	Knowing that I can count on people in times of trouble.	1	2	3	4	5	6	L6_f.
g.	A sense of closeness with others.	1	2	3	4	5	6	L6_g.
h.	Knowing I can handle difficulties.	1	2	3	4	5	6	L6_h.
i.	A willingness to express my emotions.	1	2	3	4	5	6	L6_i.
j.	Being able to accept the way things work out.	1	2	3	4	5	6	L6_j.
k.	Appreciating each day.	1	2	3	4	5	6	L6_k.
1.	Having compassion for others.	1	2	3	4	5	6	L6_1.
m.	I'm able to do better things with my life.	1	2	3	4	5	6	L6_m.
n.	New opportunities are available which wouldn't have been otherwise.	1	2	3	4	5	6	L6_n.

- 9. During the time in which your wife/partner was being treated for breast cancer, how often did you do the following to help her manage the emotional distress?
  - ☐ Does not apply because I was not with my wife/partner when
  - (-8) she was being treated for breast cancer.

		Never				Very Often	
1.	Gave her advice?	1	2	3	4	5	L10a.
2.	Went out of your way not to upset her?	1	2	3	4	5	L10b.
3.	Agreed with her to avoid an argument?	1	2	3	4	5	L10c.
4.	Acted more optimistic than you felt?	1	2	3	4	5	L10d.
5.	Kept your own problems to yourself?	1	2	3	4	5	L10e.
6.	Made up after an argument more quickly than before?	1	2	3	4	5	L10f.
7.	Apologized even when you didn't feel you were wrong?	1	2	3	4	5	L10g.
8.	Told her to calm down or relax?	1	2	3	4	5	L10h.
9.	Hid information that may upset her?	1	2	3	4	5	L10i.
10.	Stayed out of her problems?	1	2	3	4	5	L10j.
11.	Let your own problems take a "back seat" to her needs?	1	2	3	4	5	L10k.
12.	Gave her space when she was upset?	1	2	3	4	5	L101.

We thank you for all of your valued participation in this study.

		_	
 		1	





# **WOMEN'S HEALTH STUDY**

Spouse/Partner Questionnaire

Today's Date		
•		

U-ID	

SPOP

BA	CK	GRO	UND	<b>DATA</b>	SECTION	ON

	<u>BA</u>	<u>(CKGROU)</u>	ND DA'	<u>TA SECT</u>	<u>'ION</u>	
1.	Date of Birth	Month	Day _	Year		A1.
2.	Ethnic Background:	White Hispanic Native Americ	□ 1 □ 2 can □ 3	Black Asian Other	□ 4 □ 5 □ 6	A2.
3.	Religion:	Catholic Jewish Muslim	□ 1 □ 2 □ 3	Protestant Buddhist Other None	<ul><li>□ 4</li><li>□ 5</li><li>□ 6</li><li>□ 7</li></ul>	A3.
		you attend religious in Once a Month		Few Times A M	onth or More	A3a.
	3b. How importan Not at All	t are religious and s	•	fs in your life? Very Im		A3b.
4.	Are you currently worki	ng for pay outside	the home?	Yes 🗆 1	No 🗆 5	A7.
5.	If <u>yes</u> , about how many	hours per week ar	e you workii	ng for pay?		A8.
	Less than 10 1 (1)	0-20 21- (2) (2)	_	31-40	11 or more (5)	
6.	What is the highest level of 1 □ Less than 9th grade 2 □ Dropped out of high some college	school	5 □ ( 6 □ )	Completed colle Some graduate o		•
The Plea	e following two questions are check the appropriate be	are optional, but ox. (Check one)	t we hope th	at you will prov	vide this informat	ion.
7.	What is your household's	total income? (Ch	neck one)			A10.
	(1)  Less than \$10,00 (2)  \$10,000 to \$19,00 (3)  \$20,000 to \$29,00	999 (5) 🗆 \$	30,000 to \$3 40,000 to \$4 50,000 to \$5	9,999 (8)		•
8.	How many people (adults	and children) does	this income	support?		A 11.

### **PERSONAL ATTITUDES SECTION**

1. For each of these statements, please indicate the extent to which you agree or disagree by circling the appropriate number. There are no right or wrong answers. We are only interested in your opinions.

		Strongly Disagree			St A		
a.	If you don't have your health, you don't have anything.	1	2	3	4	5	L5a.
b.	There are many things I care about more than my health.	1	2	3	4	5	L5b.
c.	Good health is of only minor importance in a happy life.	1	2	3	4	5	L5c.
d.	Nothing more important than good health.	1	2	3	4	5	L5d.
e.	In uncertain times, I usually expect the best.	1	2	3	4	5	E1.
f.	It's easy for me to relax.	1	2	3	4	5	E2.
g.	If something can go wrong for me, it will.	1	2	3	4	5	E3.
h.	I always look on the bright side of things.	1	2	3	4	5	E4.
<u>i.</u>	I'm always optimistic about my future.	1	2	3	4	5	E5.
<u>j.</u>	I enjoy my friends a lot.	1	2	3	4	5	E6.
k.	It's important for me to keep busy.	1	2	3	4	5	E7.
1.	I hardly ever expect things to go my way.	1	2	3	4	5	E8.
m.	Things never work out the way I want them to.	1	2	3	4	5	E9.
n.	I don't get upset too easily.	1	2	3	4	5	E10.
0.	I'm a believer in the idea that "every cloud has a silver lining."	1	2	3	4	5	E11.
p.	I rarely count on good things happening to me.	1	2	3	4	5	E12.

#### **HEALTH SECTION**

The following questions concern your wife/partner's risk of developing breast cancer and of her having the altered gene which has been found to be associated with increased risk for breast cancer. As you may know, breast cancer runs in certain families. In some of these families, persons who develop cancer have an altered version of a gene, BRCA1. Some family members will inherit the gene and others will not.

		Not At All				All The Time		
1.	How often do you worry about your wife/partner developing breast cancer?	1	2	3	4	5		B27.
2.	To what extent do these worries interfere with your every day life?	1	2	3	4	5		B28.
3.	How often do you worry about your wife/partner having the altered gene associated with risk for breast cancer?	1	2	3	4	5		B29.
4.	To what extent do worries about your wife/partner having this altered gene interfere with your every day life?	1	2	3	4	5		В30.
5.	How often do you worry about developing cancer yourself?	1	2	3	4	5		B31.
6.	How likely do you think your wife/par (Please circle one).	tner is to	develo	p breast	cancer	in <u>the ne</u>	ar future?	В9.
	0% 10% 20% 30%	10% 50	)% 60	)% 70	)% 80	)% 90%	5 100%	
7.	Overall, what do you believe your wife at some point in her lifetime?	e/partner'	s risk is	of deve	loping l	breast can	cer	B10.
	0% 10% 20% 30% 4	10% 50	)% 60	<b>7</b> 0%	0% 80	90%	100%	
^	0 11 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1							

8. Overall, what do you believe your wife/partner's risk is of developing some other cancer **unrelated** to breast cancer **at some point in her lifetime?**B14.

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

B49.

9. How often does your wife/partner express concern and seek support from you about the risk of breast cancer to herself and women in her family?

NeverRarelySometimesOften1234

10. How much of a burden is this on you?

B50.

Not At All	A Little	Somewhat	A Great Deal		
1	2	3	4		

11. How often do you discuss genetic testing for breast cancer with your wife/partner?

B51.

Never	Rarely	Sometimes	Often
1	2	3	4

12. When you have these discussions, who generally initiates them?

B52.

You	Your Wife/partner	Equally
1	2	3

13. How satisfied are you with these discussions?

B53.

Not At All	A Little	Somewhat	A Great Deal		
1	2	3	4		

How often do you and your wife/partner get into a disagreement or conflict over the issue of her getting genetic testing for the risk of breast cancer?

B54.

Never	Rarely	Sometimes	Often		
1	2	3	4		

15. Do you think it is beneficial to have genetic testing for risk of breast cancer available to women? B55.

Not At All	Not At All A Little		A Great Deal		
1	2	3	4		

16. Do you want your wife/partner to get genetic testing for risk of breast cancer?

B56.

Not At All	A Little	Somewhat	A Great Deal		
1	2	3	4		

			Not At A		A Little	Somewhat	A Great Deal	
			1		2	3	4	
18.							account in your or breast cancer	? B58.
			Not At A	All	A Little	Somewhat	A Great Deal	
			1		2	3	4	
19.	Overa for the	ll, how impe altered ger	ortant is you ne carrying s	uscept	ion in your vibility to brea	wife/partner's dast cancer?	A Great	r to be tested  B59.
			1		2	3	Deal 4	
					2	3	4	l
19a.	Do you	believe your	wife has the		ed gene that i	increases the ris	sk of breast cand	cer? <b>B60</b> .
19b.	How con	nfident are y	ou in this be	elief?				
		Not At A Confiden					Very Confident	
		1	2	3	4	5	6 7	B61.
20.	Have y	you attended artner's risk	for breast ca	ancer	and what can	be done?	ne informed abo	out your B62.
21.	How	nuch contac			. ,	□ No	ning her risk of	oonoor? B.ca
<b>4</b> 1.	IIOW I	Very Little		au WII	ui incuicai pe		A Lot	cancer? B63.
		1		3	4 5		7	

Overall, how much do you want your opinion to be taken into account in your wife/partner's decision whether to be tested for the breast cancer gene?

B57.

17.

22.	Overa	ll, do you fee cancer and					ncerning	g your wife/partner's risk for	B43a.
		Not at All	2	3	4	5	6	Very Much	
23.	Do yo	u feel you ar testing for				out the b	enefits a	and drawbacks of genetic	B44.
		Not at All	2	3	4	5	6	Very Much	
24.	Do yo							ife/partner could do personally BRCA1 gene?	to <b>B45</b> .
		Not at All	2	3	4	5	6	Very Much	
25.	Do yo	u feel you ar options ava						and drawbacks of CA1 gene?	B46.
		Not at All	2	3	4	5	6	Very Much	
26.	Do yo	•	_	•		1 gene	? 🗆 <b>C</b> !	d mean for your children if you heck here if you do not hav	
		Not at All	2	3	4	5	-8)	Very Much	
27.	How o	confident are	you that	t your wit	fe/partne	r:			
	27a.	Will make associated					be teste	d for BRCA1, the altered gene	B48a.
		Not at All	2	3	4	5	6	Very Much	
	27b.	Would cop	e effecti	vely with	the findi	ing that	she had	the altered BRCA1 gene?	B48b.
		Not at All	2	3	4	5	6	Very Much	
	27c.	Would make have the alt				rning he	er option	s if she were found to	В48с.
		Not at All	2	3	4	5	6	Very Much	
	27d.	Would be a long haul if						nd cope effectively over the 11 gene?	B48d.
		Not at All	2.	3	4	5	6	Very Much	

Please indicate the extent to which you agree or disagree with the following statements using the 1 (strongly disagree) to 5 (strongly agree) scale. Please try to provide your opinion for all of these questions. However, if you feel you simply do not know enough to have an opinion, check the "I don't know" box.

		Strong Disag		***********		trongly Agree	I Don't Know	
a.	Mammography is effective in the early detection of breast cancer in women.	1	2	3	4	5	9	B20a.
b.	Breast cancer that is detected early is curable.	1	2	3	4	5	9	В20ь.
c.	Mammography can detect lumps that cannot be felt by a woman or by her doctor.	1	2	3	4	5	9	В20с.
d.	If more women went for breast screening, there would be fewer deaths from breast cancer.	1	2	3	4	5	9	B20d.
e.	If a lump is found in a woman's breast, it is usually too late to do anything about it.	1	2	3	4	5	9	B20f.
f.	There are so many things that could happen to someone's health that it is pointless for a woman to worry about breast cancer.	1	2	3	4	5	9	B20i.
g.	If a woman were found to have breast cancer, the chances of it being cured are high.	1	2	3	4	5	9	B20m.
h.	Once a woman has had effective treatment for breast cancer, she will not get it again.	1	2	3	4	5	9	B20n.
i.	A mastectomy totally eliminates a woman's risk for breast cancer.	1	2	3	4	5	9	B20o.
j.	All women who have the altered version of the BRCA1 gene will get breast cancer.	1	2	3	4	5	9	В20р.
k.	Most of the breast cancer in the United States is due to altered versions of the BRCA1 gene.	1	2	3	4	5	9	B20q.
1.	The next decade is going to bring major advances in the detection and treatment of breast cancer.	1	2	3	4	5	9	B20r.
m.	Over the next decade, medical break-through's are going to make breast cancer much less of a threat to women's health.	1	2	3	4	5	9	B20s.

29. If your wife/partner were to take the test and find that she <u>did not</u> have the altered version of the BRCA1 gene which is associated with high risk for breast cancer, what would you expect your reactions to be?

		Strong Disagr				rongly Agree	
a.	I would feel wonderful.	1	2	3	4	5	B18a.
b.	I would feel I had been told what I knew all along.	1	2	3	4	5	B18b.
c.	I would feel relieved.	1	2	3	4	5	B18c.
d.	I would not believe the results.	1	2	3	4	5	B18d.
e.	I would fall apart emotionally.	1	2	3	4	5	B18e.
f.	I would feel guilty.	1	2	3	4	5	B18f.
g.	I would still feel anxious.	1	2	3	4	5	B18g.
h.	I would feel angry.	1	2	3	4	5	B18h.
i.	I would feel prepared for the future.	1	2	3	4	5	B18i.
j.	I would feel I had done all I needed to do.	1	2	3	4	5	B18j.
k.	I would not feel very differently.	1	2	3	4	5	B18k.

30. If your wife/partner were to take the test and find out that she <u>had</u> the altered version of the BRCA1 gene for breast cancer, what would you expect your reactions to be?

		Strong Disagi				rongly Igree	
a.	I would feel relieved about being more certain.	1	2	3	4	5	B19a.
b.	I would feel I had been told what I knew all along.	1	2	3	4	5	B19b.
c.	I would not believe the results.	1	2	3	4	5	В19с.
d.	I would feel guilty.	1	2	3	4	5	B19d.
e.	I would feel depressed.	1	2	3	4	5	B19e.
f.	I would feel worried about the future.	1	2	3	4	5	B19f.
g	I would fall apart emotionally.	1	2	3	4	5	B19g.
h.	I would feel anxious.	1	2	3	4	5	B19h.
i.	I would feel angry.	1	2	3	4	5	B19i.
j.	I would not feel very differently.	1	2	3	4	5	B19j.
k.	I would want my daughters to be tested as soon as possible.		2	3	4	5	B19k.

31. The following questions concern your involvement in your wife/partner's health care:

		Not at All				Very Often
a.	To what extent do you go with your wife/partner to her appointments with doctors?	1	2	3	4	5
b.	To what extent do you talk with your wife/partner's doctor or other medical personnel about her risk of cancer?	1	2	3	4	5
c.	To what extent do you keep track of what your wife/partner needs to do about her risk of cancer?	1	2	3	4	5
d.	To what extent do you change your activities to look after your wife/partner?	1	2	3	4	5

H35a.

Н35Ь.

Н35с.

H35d.

- 32. If my wife/partner were tested and found to have the altered BRCA1 gene carrying the altered BRCA1 gene carrying increased risk of breast cancer, I would want her to manage her risk by relying on:
  - a. Being extra careful about breast self-examination and regular medical examinations.

B64a.

Not at All						Very Much So
1	2	3	4	5	6	7

b. Getting preventive surgery.

B64b.

Not at All						Very Much So
1	2	3	4	5	6	7

33. I do not believe it would be my place to tell my wife/partner my opinion about what she should do about her risk of breast cancer.

B65.

Strongly Disagree						Strongly Agree
1	2	3	4	5	6	7

## **RELATIONSHIPS**

1.		Is there anyone in your life with whom you can share your most private feelings without holding back?									
	(1) ☐ <b>Y</b> es	(5) No									
2.	Can you share your m	ost private feelings v	vith your wife/pa	artner	without holding back?	C21a.					
	(1) ☐ <b>Yes</b>	(5) \( \sup \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \									
3.	Is there anyone beside without holding back?		vith whom you c	can sl	nare your most private feelings	C21b.					
	(1) <b>Yes</b>	(5) 🗆 N o									
4.	Have any of the event (Check All That A		ned to you in the	past	six months?	D1 (a-m)					
a.	☐ You retired or wer off from work.	e fired or laid	g.		A close family member was seriously ill or injured.						
b.	☐ You were unemple looking for work.		h.		You had a marital separation or divorce.						
c.	☐ Your spouse retire fired or laid off fr		i.		You had serious troubles with relatives or close friends.						
d	☐ Your spouse was and looking for w		j.		Your spouse had troubles with relatives or close						
e.	☐ You had problems	with the	1		friends.						
f.	police or court.	us financial	k. l.		A close family member died.  A close friend or relative died.						
1.	<ul><li>You got into serior difficulties.</li></ul>	us Illianciai	n.		You were seriously ill or injured	·•					

### **MARRIAGE SECTION**

Most people have disagreements in their relationships. Please indicate, using check marks the extent of agreement or disagreement experienced between you and your wife/partner on the following issues **DURING THE PAST MONTH**.

		Always Agree	Almost Always Agree	Occa- sionally Disagree	Fre- quently Disagree	Almost Always Disagree	Always Disagree	
1.	Handling family finances	1	2	3	4	5	6	F
2.	Matters of recreation	1	2	3	4	5	6	F
3.	Religious matters	1	2	3	4	5	6	I
4.	Demonstration of affection	1	2	3	4	5	6	I
5.	Friends	1	2	3	4	5	6	H
6.	Sex relations	1	2	3	4	5	6	F
7.	Conventionality (correct or proper behavior)	1	2	3	4	5	6	1
8.	Philosophy of life	1	2	3	4	5	6	I
9.	Ways of dealing with parents or in-laws	1	2	3	4	5	6	]
10.	Aims, goals, and things believed important	1	2	3	4	5	6	Н
11.	Amount of time spent together	1	2	3	4	5	6	Н
12.	Making major decisions	1	2	3	4	5	6	Н
13.	Household tasks	1	2	3	4	5	6	Н
14.	Leisure time interests and activities	1	2	3	4	5	6	Н
15.	Career decisions	1	2	3	4	5	6	H

F	<del></del>	All of the Time	Most of the Time	More Often than Most	Occa- sionally	Rarely	Never	
16.	How often do you discuss or have you considered divorce, separation, or terminating your relationship?	1	2	3	4	5	6	H16.
17.	How often do you or your wife/partner leave the house after a fight?	1	2	3	4	5	6	H17.
18.	In general, how often do you think that things between you and your wife/partner are going well?	1	2	3	4	5	6	H18.
19.	Do you confide in your wife/partner?	1	2	3	4	5	6	H19.
20.	Do you ever regret that you married (or lived together)?	1	2	3	4	5	6	H20.
21.	How often do you and your wife/partner quarrel?	1	2	3	4	5	6	H21.
22.	How often do you and your wife/partner "get on each other's nerves?"	1	2	3	4	5	6	Н22.

	Every Day	Almost Every Day	Occa- sionally	Rarely	Never
o you kiss your ife/partner?	1	2	3	4	5

		All of Them	Most of Them	Some of Them	Very few of Them	None of Them
24.	Do you and your wife/partner engage in					
	outside interests together?	1	2	3	4	5

H23.

H24.

How often would you say the following events occur between you and your wife/partner?

		Never	Less than once a month	About twice a month	About twice a week	Once a day	More Often
25.	Have a stimulating exchange of ideas	1	2	3	4	5	6
26.	Laugh together	1	2	3	4	5	6
27.	Calmly discuss something	1	2	3	4	5	6
28.	Work together on a project	1	2	3	4	5	6

H25.

H26.

H27.

H28.

These are some things couples sometimes agree and sometimes disagree upon. Indicate if either item below caused differences of opinions or were problems in your relationship during the past month. (Check ves or no).

- 29. Being too tired for sex.
- (1) **Yes**
- (5) No

H29.

- 30. Not showing love.
- (1) \( \subseteq \text{Yes}
- (5) No

H30.

31. The following scale represents different degrees of happiness in your relationship. The middle point "happy" represents the degree of happiness of most relationships. Please circle the number which best describes the degree of happiness, all things considered, of your relationship.

H31.

Extremely Unhappy	Fairly Unhappy	A Little Unhappy	Нарру	Very Happy	Extremely Happy	Perfect
1	2	3	4	5	6	7

32. Please check <u>one</u> of the following statements to best describe how you feel about the **future** of your relationship.

H32.

- (1).\_\_\_\_I want desperately for my relationship to succeed, and would go to almost any length to see that it does.
- (2).\_\_\_\_I want very much for my relationship to succeed, and will do all I can to see that it does.
- (3).\_\_\_I want very much for my relationship to succeed, and will do my fair share to see that it does.
- (4). It would be very nice if my relationship succeeded, but <u>I can't</u> do much more than I am doing now to help it succeed.
- (5). <u>It would be nice if it succeeded, but I refuse to do any more than I am doing now to keep the relationship going.</u>
- (6). My relationship can never succeed, and there is no more that I can do to keep the relationship going.

33. Considering only the positive feelings you have toward your wife/partner, and ignoring the negative ones, please rate how positive these feelings are:

H33.

Not At All Positive										remely sitive
ſ	1	2	3	4	5	6	7	8	9	10

34. Considering only the negative feelings you have toward your wife/partner, and ignoring the positive ones, please rate how negative these feelings are:

H34.

Not A Nega									remely gative
1	2	3	4	5	6	7	8	9	10

#### **CURRENT FAMILY SECTION**

Please indicate the extent to which each of the following items describes your current family (your household).

		Strongly Disagree				trongly Agree	
1.	Planning family activities is difficult because we misunderstand each other.	1	2	3	4	5	M1.
2.	In times of crisis we can turn to each other for support.	1	2	3	4	5	M2.
3.	We cannot talk to each other about the sadness we feel.	1	2	3	4	5	М3.
4.	Individuals are accepted for who they are.	1	2	3	4	5	M4.
5.	We avoid discussing our fears and concerns.	1	2	3	4	5	M5.
6.	We can express feelings to each other.	1	2	3	4	5	M6.
7.	There are lots of bad feelings in the family.	1	2	3	4	5	М7.
8.	We feel accepted for who we are.	1	2	3	4	5	M8.
9.	Making decisions is a problem for our family.	1	2	3	4	5	М9.
10.	We are able to make decisions about how to solve problems.	1	2	3	4	5	M10.
11.	We don't get along well together.	1	2	3	4	5	M11.
12.	We confide in each other.	1	2	3	4	5	M12.

## YOUR HEALTH AND MOOD SECTION

1.	In gen	eral, would	you say yo	our health is:			I	1.
	(1)	Excellent	(2) \( \subseteq \text{ Ve}	ery Good	(3) Good	(4) 🗆 Fair	(5) Poor	
2.	you fe	lt sad, blue,	or depress		ks or more when near h you lost all interest it lo for fun?		I14	4.
		(1)	□ Yes	(5) No (SI	kip to Question 3)			
	2a.	If there was	s such a tv	vo-week perio	od, did your work or r	elationships	114	1a.
		(1)	□ Yes	(5) \( \sum \) N o				
	2b.	If there was		vo-week perio	od, did you get counse	eling or	I14	₿b.
		(1)	□ Yes	(5) 🗆 N o				
	2c.	If there we condition?	as such a t	wo-week peri	od, did you get medic	ation for this	I14	4c.
		(1)	□ Yes	(5) 🗆 N o				
3.	you fe	elt sad, blue,	or depress		weeks or more when h you lost all interest i lo for fun?		I1	12.
		(1)	□ Yes	(5) □ No (SI	kip to Question 4)			
	3a.	If there we or relation			riod (in the past 6 m	onths), did your we	ork I12	2a.
		(1)	□ Yes	(5) 🗆 N o				
	3b.	If there was			riod (in the past 6 m	onths), did you get	I12	2b.
		(1)	□ Yes	(5) 🗆 N o				
	3c.	If there was			riod, (in the past 6 m	nonths) did you get	I12	2c.
		(1)	□ Yes	(5) 🗆 N o				
4.		ou currently ssion or emo			psychotherapy, or me	dication for	113	3.
		(1)	□ Yes	(5) \( \sup \) N o				

### **SYMPTOMS OF STRAIN SECTION**

LISTED BELOW ARE SOME SYMPTOMS OF STRAIN THAT PEOPLE SOMETIMES HAVE. Please Read Each One Carefully And Check The Answer Which Best Reflects How Much That Symptom Has Bothered You During the <u>Past Three Months</u>.

		I <u>Not at all</u>	2 <u>A little</u>	3 <u>Ouite a bit</u>	4 Extremely
1.	Suddenly scared for no reason	1	2	3	4
2.	Feeling fearful	1	2	3	4
3.	Faintness, dizziness, or weakness	1	2	3	4
4.	Nervousness or shakiness inside	1	2	3	4
5.	Heart pounding or racing	1	2	3	4
6.	Trembling	1	2	3	4
7.	Feeling tense or keyed up	11	2	3	4
8.	Headaches	1	2	3	4
9.	Spells of terror or panic	1	2	3	4
10.	Feeling restless, can't sit still	1	2	3	4
11.	Feeling low in energyslowed down	1	2	3	4
12.	Blaming yourself for things	1	2	3	4
13.	Crying easily	1	2	3	4
14.	Loss of sexual interest or pleasure	1	2	3	4
15.	Poor appetite	1	2	3	4
16.	Difficulty falling asleep, staying asleep	1	2	3	4
17.	Feeling hopeless about the future	1	2	3	4
18.	Feeling blue	1	2	3	4
19.	Feeling lonely	1	2	3	4
20.	Feeling trapped or caught	1	2	3	4
21.	Worrying too much about things	1	2	3	4
22.	Feeling no interest in things	1	2	3	4
23.	Thoughts of ending your life	1	2	3	4
24.	Feeling everything is an effort	1	2	3	4
25.	Feelings of worthlessness	1	2	3	4

16

#### **COPING SECTION**

1. Imagine that you are afraid of the dentist and have to get some dental work done. Which of the following would you do? Please answer **yes** or **no** for each choice.

		YES	NO	
a.	I would ask the dentist exactly what s/he was going to do.	1	5	] 1
b.	I would take a tranquilizer or have a drink before going.	1	5	]
c.	I would try to think about pleasant memories.	1	5	]
d.	I would want the dentist to tell me when I would feel pain.	1	5	]
e.	I would try to sleep.	1	5	]
f.	I would watch all the dentist's movements and listen for the sound of the drill.	1	5	1
g.	I would watch the flow of water from my mouth to see if it contained blood.	1	5	]
h.	I would do mental puzzles in my mind.	1	5	]

2. Imagine that you are being held hostage by a group of armed terrorists in a public building. Which of the following would you do?

		YES	NO
a.	I would sit by myself and have as many daydreams and fantasies as I could.	1	5
b.	I would stay alert and try to keep myself from falling asleep.	1	5
c.	I would exchange life stories with the other hostages.	1	5
d.	If there was a radio present, I would stay near it and listen to the bulletins about what the police were doing.	1	5
e	I would watch every movement of my captors and keep an eye on their weapons.	1	5
f	I would try to sleep as much as possible.	1	5
g.	I would think about how nice it's going to be when I get home.	1	5
h.	I would make sure I knew where every possible exit was.	1	5

3. Imagine that due to a large drop in sales, it is rumored that several people in your department at work will be laid off. Your supervisor has turned in an evaluation of your work for the past year. The decision about lay-off has been made and will be announced in several days. Please answer yes or no for each choice.

		YES	NO	
a.	I would talk to my fellow workers to see if they knew anything about what the supervisor's evaluation of me said.	1	5	L3_1
b.	I would review the list of duties for my present job and try to figure out if I had fulfilled them all.	1	5	L3_2
c.	I would go to the movies to take my mind off things.	1	5	L3_3
d.	I would try to remember any arguments or disagreements I might have had with the supervisor that would have lowered his opinion of me.	1 .	5	L3_4
e.	I would push all thoughts of being laid off out of my mind.	1	5	L3_5
f.	I would tell my spouse that I'd rather not discuss my chances of being laid off.	1	5	L3_6
g.	I would try to think which employees in my department the supervisor might have thought had done the worst job.	1	5	L3_7
h.	I would continue doing my work as if nothing special was happening.	1	5	L3_8

4. Imagine that you are on an airplane, 30 minutes from your destination, when the plane unexpectedly goes into a deep dive and then suddenly levels off. After a short time, the pilot announces that nothing is wrong, although the rest of the ride may be rough. You, however, are not convinced that all is well. Please answer yes or no for each choice.

		YES	NO	
a.	I would carefully read the information provided about safety features in the plane and make sure I knew where the emergency exits were.	1	5	<b>L4</b> _1
b.	I would make small talk with the passenger beside me.	1	5	L4_2
c.	I would watch the end of the movie, even if I had seen it before.	1	5	L4_3
d.	I would call for the flight attendant and ask her/him exactly what the problem was.	1	5	L4_4
e.	I would order a drink or tranquilizer from the stewardess.	1	5	L4_5
f.	I would listen carefully to the engines for unusual noises and would watch the crew to see if their behavior was out of the ordinary.	1	5	L4_6
g.	I would talk to the passenger beside me about what might be wrong.	1	5	L4_7
h.	I would settle down and read a book or magazine or write a letter.	1	5	L4_8

5. This set of questions deals with ways you've been coping with the stress in your life that goes with your wife/partner possibly having the altered BRCA1 gene associated with risk for breast cancer. Obviously, different people deal with this stress in different ways, but we are interested in how you've tried to deal with it. Each item says something about a particular way of coping. We wantto 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 it seems to be working, but just whether or not you're doingit. Use these response choices below and try not to let one answer influence another. Make your answers as true FOR YOU as you can.

		I haven't been doing this at all 1	I've been doing this a little bit 2	I've been doing this some 3	I've been doing this a lot 4	
a.	I've been turning to work or other activities to take my mind off things.	1	2	3	4	L,
b.	I've been concentrating my efforts on doing something about her situation.	1	2	3	4	L
c.	I've been saying to myself "this isn't possible."	1	2	3	4	L
d.	I've been using alcohol or other drugs to make myself feel better.	1	2	3	4	L'
e.	I've been getting emotional support from others.	1	2	3	4	L.
f.	I've been giving up trying to deal with it.	1	2	3	4	L
g.	I've been taking action to try to make the situation better.	1	2	3	4	L
h.	I've been refusing to believe that it is possible she has the gene.	1	2	3	4	L'
i.	I've been saying things to let my unpleasant feelings escape.	1	2	3	4	L
j.	I've been using alcohol or other drugs to help me get through it.	1	2	3	4	L
k.	I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4	L
l.	I've been trying to come up with a strategy for what to do.	1	2	3	4	L
m.	I've been getting comfort and understanding from someone.	1	2	3	4	L

		I haven't been doing this at all I	I've been doing this a little bit 2	I've been doing this some 3	I've been doing this a lot 4	
n.	I've been giving up the attempt to cope.	1	2	3	4	L7
0.	I've been accepting the possibility that she might have the gene.	1	2	3	4	L7
o.	I've been expressing my negative feelings.	1	2	3	4	L7
<b>1</b> .	I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4	L7
•	I've been learning to live with the possibility she might have the gene.	1	2	3	4	L7
•	I've been thinking hard about what steps to take.	1	2	3	4	L7
•	I've been praying or meditating.	1	2	3	4	L7
	I've been making fun of the situation.	11	2	3	4	L7
•	I've been giving pep talks and encouraging my wife/partner.	1	2	3	4	L7
√.	I've been denying or hiding my anger around my wife/partner.	1	2	3	4	L
•	I've been denying or hiding my own worries around my wife/partner.	1	2	3	4	L,
•	I've been trying to give my wife/partner opportunities to talk about her worries.	1	2	3	4	L
i.	I've been trying to find out what my wife/partner is feeling.	1	2	3	4	L
a.	I've been avoiding talking about my own problems around my wife/partner.	1	2	3	4	L7
b.	I've acted more positive around my wife/partner than I feel.	1	2	3	4	L7

- 6. For each of the statements on the following page, indicate the degree to which this change occurred in your life as a result of your wife/partner possibly having an altered gene associated with greater risk for breast cancer. Please use the following scale:
  - 1 = I experienced <u>no change</u> as a result of my wife/partner possibly having an altered gene associated with greater risk for breast cancer.
  - 2 = I experienced this change to a <u>very small degree</u> as a result of my wife/partner possibly having an altered gene associated with greater risk for breast cancer.
  - 3 = I experienced this change to a <u>small degree</u> as a result of my wife/partner possibly having an altered gene associated with greater risk for breast cancer.
  - 4 = I experienced this change to a **moderate degree** as a result of my wife/partner possibly having an altered gene associated with greater risk for breast cancer.
  - 5 = I experienced this change to a **great degree** as a result of my wife/partner possibly having an altered gene associated with greater risk for breast cancer.

6 = I experienced this change to a <u>very great degree</u> as a result of my wife/partner possibly having an altered gene associated with greater risk for breast cancer.

Vory

		No Change	Very Small Degree	Small Degree	Moderate Degree	Great Degree	Very Great Degree	
a.	My priorities about what is important in life.	1	2	3	4	5	6	L6_a.
b.	I'm more likely to try to change things which need changing.	1	2	3	4	5	6	L6_b.
c.	An appreciation for the value of my own life.	1	2	3	4	5	6	L6_c.
d.	A feeling of self-reliance.	1	2	3	4	5	6	L6_d.
e.	A better understanding of spiritual matters.	1	2	3	4	5	6	L6_e.
f.	Knowing that I can count on people in times of trouble.	1	2	3	4	5	6	L6_f.
g.	A sense of closeness with others.	1	2	3	4	5	6	L6_g.
h.	Knowing I can handle difficulties.	1	2	3	4	5	6	L6_h.
i.	A willingness to express my emotions.	1	2	3	4	5	6	L6_i.
j.	Being able to accept the way things work out.	1	2	3	4	5	6	L6_j.
k.	Appreciating each day.	1	2	3	4	5	6	L6_k.
l.	Having compassion for others.	1	2	3	4	5	6	L6_l.
m.	I'm able to do better things with my life.	1	2	3	4	5	6	L6_m.
n.	New opportunities are available which wouldn't have been otherwise.	1	2	3	4	5	6	L6_n.

Thank you for your valued participation in this study.

	١	١.		
			_	





# WOMEN'S HEALTH STUDY

Pre-Results Questionnaire

1

ID	)	

#### PRE-RESULTS QUESTIONNAIRE - A

This questionnaire, from the Women's Health Study being conducted by the University of Michigan Medical Center and the University of Pennsylvania Cancer Center, is being given to women who are now being offered the opportunity to learn whether they have the altered gene associated with risk for early breast cancer. Again, we remind you that many of the questions are new. Some of them were asked in the first questionnaire you completed. We are asking them again because we are interested in feelings and attitudes which may change over time. THANK YOU VERY MUCH!

### **GENETIC TESTING-SECTION 1**

1.	Have you met with anyone to have genetic counseling?	B24.
	1 5	~
	☐ Yes ☐ No	
_		
2.	Has any member of your family met with someone to have genetic counseling?	B25.

3.	Do you believe you	have the altered gene that increases the risk of breast cancer?	B72.
	1	5	
	□ Ves	$\sqcap$ No	

4. How confident are you in this belief?

☐ Yes

 $\square$  No

Not At A Confider	Co	Very Confident				
1	2	3	4	5	6	7

B73.

5. As the opportunity to get testing has approached, has your interest in getting results changed? B74.

Decreased	Decreased	N o	Increased	Increased
Very Much	Slightly	Change	Slightly	Very Much
1	2	3	4	5

#### PERSONAL ATTITUDES SECTION

1. For each of these statements, please indicate the extent to which you agree or disagree by circling the appropriate number. There are no right or wrong answers. We are only interested in your opinions.

		Strong Disagi				rongly Igree	
a.	If you don't have your health, you don't have anything.	1	2	3	4	5	L5a.
b.	There are many things I care about more than my health.	1	2	3	4	5	L5b.
c.	Good health is of only minor importance in a happy life.	1	2	3	4	5	L5c.
d.	There is nothing more important than good health.	1	2	3	4	5	L5d.
e.	In uncertain times, I usually expect the best.	1	2	3	4	5	E1.
f.	It's easy for me to relax.	1	2	3	4	5	E2.
g.	If something can go wrong for me, it will.	1	2	3	4	5	E3.
h.	I always look on the bright side of things.	1	2	3	4	5	E4.
i.	I'm always optimistic about my future.	1	2	3	4	5	E5.
j	I enjoy my friends a lot.	1	2	3	4	5	E6.
k.	It's important for me to keep busy.	1	2	3	4	5	E7.
1.	I hardly ever expect things to go my way.	1	2	3	4	5	E8.
m.	Things never work out the way I want them to.	1	2	3	4	5	E9.
n.	I don't get upset too easily.	1	2	3	4	5	E10.
0.	I'm a believer in the idea that "every cloud has a silver lining."	1	2	3	4	5	E11.
p.	I rarely count on good things happening to me.	1	2	3	4	5	E12.

# **GENETIC TESTING-SECTION 2**

he ge	enetic test to learn se check one	n if your cancer	r is the type that	ancer, would y truns in familie	ou consider taking es?
a	I will <u>d</u>	efinitely take t	he test <u>immedia</u>	tely when it be	comes available.
)	I will <u>d</u>	efinitely take t	he test, but I am	not sure if im	mediately.
>	I will p	robably take th	ne test immediat	ely when it bed	comes available.
i	I will p	robably take th	ne test, but not i	mmediately.	
è	I am <u>ur</u>	ndecided wheth	ner I will take th	e test	
· <u> </u>	I will p	robably not tal	ke the test.		
3	I will <u>d</u>	efinitely not ta	ke the test.		
ou m	e following scale hay be at increase  Not At All  Distressing	e, indicate how ed risk for recu	rrence breast ca	s for you to kn incer because o	ow that of your family history  Very  Distressing
	1	2	3	4	5
				I 4+	1 1 1
Jose .		· · · · · · · · · · · · · · · · · · ·			
How o	distressing it is to tered gene associ  Not At All  Distressing	be given the	opportunity to b	l e tested for the	
How de he ali	distressing it is to tered gene associ	be given the	opportunity to b	l e tested for the	e BRCA-1 gene,
he al	distressing it is to tered gene associ  Not At All  Distressing	be given the ated with incre	opportunity to be ased risk for broader	pe tested for the east cancer?	Very Distressing
he al	distressing it is to tered gene associ  Not At All Distressing  1  distressed do you	be given the ated with incre	opportunity to be ased risk for broader	pe tested for the east cancer?	Very Distressing
he al	distressing it is to tered gene associ  Not At All Distressing  1  distressed do you before you recei	be given the ated with incre	opportunity to be ased risk for broader	pe tested for the east cancer?	Very Distressing  5  Or the BRCA-1
How of	distressing it is to tered gene associ  Not At All Distressing  1  distressed do you before you recei  Not At All Distressed	2 expect to be veresults)?	opportunity to be ased risk for broad when you actual	be tested for the east cancer?  4  Bly get tested for the east cancer?	Very Distressing  5  Or the BRCA-1  Very Distressed  5
How of	distressing it is to tered gene associ  Not At All Distressing  1  distressed do you (before you recei  Not At All Distressed  1  distressed  1	2 expect to be veresults)?	opportunity to be ased risk for broad when you actual	be tested for the east cancer?  4  Bly get tested for the east cancer?	Very Distressing  5  Or the BRCA-1  Very Distressed  5

Overall, to what extent do you welcome the opportunity to be tested for the BRCA gene?    Not	erall, to what extent do you welcome the opportunity to be tested for the BRCAne?    Not
Not At All	Not At All Very Much So  1 2 3 4 5  Not At All All The Time
Not At All   All The Time	At All         Much So           1         2         3         4         5   Not At All All The Time
How often do you worry about again developing breast cancer?  To what extent do these worries interfere with your every day life?  How often do you worry about having the altered gene carrying risk for breast cancer?  To what extent do these worries about having the altered gene carrying risk for breast cancer?  To what extent do these worries you have about having this altered gene interfere with your every day life?  Before your diagnosis of breast cancer, how likely did you think you were to develop breast cancer, compared to other women? (Please circle one)	Not At All All The Time
How often do you worry about again developing breast cancer?  To what extent do these worries interfere with your every day life?  How often do you worry about having the altered gene carrying risk for breast cancer?  To what extent do these worries you have about having this altered gene interfere with your every day life?  Before your diagnosis of breast cancer, how likely did you think you were to develop breast cancer, compared to other women? (Please circle one)	
How often do you worry about again developing breast cancer?  To what extent do these worries interfere with your every day life?  How often do you worry about having the altered gene carrying risk for breast cancer?  To what extent do these worries you have about having this altered gene interfere with your every day life?  Before your diagnosis of breast cancer, how likely did you think you were to develop breast cancer, compared to other women? (Please circle one)	
Interfere with your every day life?  How often do you worry about having the altered gene carrying risk for breast cancer?  To what extent do these worries you have about having this altered gene interfere with your every day life?  Before your diagnosis of breast cancer, how likely did you think you were to develop breast cancer, compared to other women? (Please circle one)  Much Less  Much More	w often do you worry about again 1 2 3 4 5 reloping breast cancer?
having the altered gene carrying risk for breast cancer?  To what extent do these worries you have about having this altered gene interfere with your every day life?  Before your diagnosis of breast cancer, how likely did you think you were to develop breast cancer, compared to other women? (Please circle one)  Much Less  Much More	
have about having this altered gene interfere with your every day life?  Before your diagnosis of breast cancer, how likely did you think you were to develop breast cancer, compared to other women? (Please circle one)  Much Less  Much More	ring the altered gene carrying risk
to develop breast cancer, compared to other women? (Please circle one)  Much Less  Much More	re about having this altered gene
	develop breast cancer, compared to other women? (Please circle one)
Likely	Much Less Much More Likely Likely
1 2 3 4 5	1 2 3 4 5
When was the last time you had a mammography? (99)	· · · · · · · · · · · · · · · · · · ·

\_times

(99)  $\square$  This question does not apply because of surgery.

15.	How	How confident are you that you will perform breast self examination (BSE)								
	15a.	as f <b>reque</b>	ently as	s needed?	(9) 🗆 l	Does Not	Apply E	Because of S	Surgery	B34a.
		Not at All	2	3	4	5	6 V	ery Much S	do .	
	15b.	as carefu	ılly an	d compet	• _	_		ly Recause	of Surgery	B34b.
		Not at All	2	3		5	•	ery Much S	0 ,	

For each of the following areas of your life, you will be asked to make <u>two</u> ratings. First, indicate how much these decisions have been affected by <u>the possibility that you have an increased risk for breast cancer</u> (based on your family history). Second, how much would these decisions be affected by <u>the results of genetic testing</u>?

1	2	3	4	5
Not at all affecte	ed			Very much affected

			been ut inci bre		risk fo	•	l			ted by tic test		
16.	Decisions about having children	1	2	3	4	5	1	2	3	4	5	B. B.
17.	Decisions about form of birth control	1	2	3	4	5	1	2	3	4	5	B B
18.	Decisions about which steps to take to prevent the recurrence of breast cancer	1	2	3	4	5	1	2	3	4	5	B B:
19.	Decisions about work and career	1	2	3	4	5	1	2	3	4	5	B B
20.	Decisions about savings and financial planning	1	2	3	4	5	1	2	3	4	5	B:
21.	Decisions about plans for the future	1	2	3	4	5	1	2	3	4	5	B <sub>4</sub>

Answer the follow	<u>ving qu</u>	<u>estion</u>	only i	f you	<u>have d</u>	<u>aughte</u>	rs.				
		ection, I	Life Eve	ents)						B41.	
Plans for your daughter's future	1	2	3	4	5	1	2	3	4	5	B42a B42b
	□ Does Not (Skip to	□ Does Not Apply (Skip to Next Se	Does Not Apply (Skip to Next Section, I  Have been at high risk  Plans for your  1 2	Does Not Apply (Skip to Next Section, Life Events Section)  Have been affected at high risk for been section.  Plans for your 1 2 3	Does Not Apply (Skip to Next Section, Life Events)  Have been affected by at high risk for breast c  Plans for your  1 2 3 4	□ Does Not Apply (Skip to Next Section, Life Events)    Have been affected by being at high risk for breast cancer     Plans for your   1   2   3   4   5	Does Not Apply (Skip to Next Section, Life Events)  Have been affected by being at high risk for breast cancer reserved.  Plans for your 1 2 3 4 5 1	(Skip to Next Section, Life Events)  Have been affected by being at high risk for breast cancer results of Plans for your 1 2 3 4 5 1 2	Does Not Apply (Skip to Next Section, Life Events)    Have been affected by being at high risk for breast cancer   Would be affected by being at high risk for breast cancer   Plans for your   1   2   3   4   5   1   2   3	Does Not Apply (Skip to Next Section, Life Events)    Have been affected by being at high risk for breast cancer   Would be affected by results of genetic test	Does Not Apply (Skip to Next Section, Life Events)    Have been affected by being at high risk for breast cancer   Would be affected by the results of genetic testing

## **LIFE EVENTS SECTION**

1.	e any of the following events happened to y eck All That Apply)	ou in <u>t</u>	ne past	six months? D1(a-m)
a.	You retired, were fired, or laid off from work.	g.		A close family member was seriously ill or injured.
b.	You were unemployed and looking for work.	h.		You had a marital separation or divorce.
c.	Your spouse retired, was fired, or laid off from work.	i.		You had serious troubles with relatives or close friends.
d	Your spouse was unemployed and looking for work.	j.		Your spouse had troubles or difficulties with relatives or close
e.	You had problems with the police or			friends.
	court.	k.		A close family member died.
f.	You got into serious financial	1.		A close friend or relative died.
	difficulties.	m.		You were seriously ill or injured.

#### **MARRIAGE SECTION**

The following questions apply to persons who are <u>married or living with</u> a partner. If you are not married or living with a partner, check the appropriate box and please skip to the Next Section, MOOD.

	Not man	rried or livi	ng with a	partner $\square$			Ha	ι.
box t	persons have disagreement of a partner <b>DURING THE</b>	greement	or disagn	reement e	xperienc	eck the a	ppropriate en you an	e ıd
		6	5	4	3	2	1	
		Always Agree	Almost Always Agree	Occa- sionally Disagree	Fre- quently Disagree	Almost Always Disagree	Always Disagree	
1.	Religious matters							I
2.	Demonstration of affection							E
3.	Sex relations		,					F
4.	Conventionality (correct or proper behavior)							F
5.	Making major decisions				<del></del>			Н
6.	Career decisions		· · · · · · · · · · · · · · · · · · ·					H
		1	2	3	4	5	6	
		All of the time	Most of the time	More often than most	Occa- sionally	Rarely	Never	
7.	How often do you discuss or have you considered divorce, separation, or terminating your							Н

H20.

H21.

H22.

relationship?

together)?

10.

Do you ever regret that you

How often do you and your

husband/partner quarrel?
How often do you and your

husband/partner "get on each other's nerves?"

married (or are living

		5	4	3	2	1
		All of Them	Most of Them	Some of Them	Very few of Them	None of Them
11.	Do you and your husband/partner engage in outside interests together?					

H24.

How often would you say the following events occur between you and your husband/partner?

		1	2	3	4	5	6
		Never	Less than once a month	About twice a month		Once a day	More Often
12.	Have a stimulating exchange of ideas						
13.	Calmly discuss something						
14.	Work together on a project						

H25.

H27.

H28.

15. Considering only the positive feelings you have toward your husband/partner, and ignoring the negative ones, please rate how positive these feelings are:

H33.

Not A Posi							***************************************		emely sitive
1	2	3	4	5	6	7	8	9	10

16. Considering only the negative feelings you have toward your husband/partner, and ignoring the positive ones, please rate how negative these feelings are:

H34.

Not A Nega									remely gative
1	2	3	4	5	6	7	8	9	10

The following questions concern your husband's involvement in your health care. 17.

		Never				Very Often	
a.	How often does your husband/partner go with you to your appointments with doctors?	1	2	3	4	5	H35a.
b.	How often does your husband/partner talk with your doctor or other medical personnel about your risk for breast cancer?	1	2	3	4	5	H35b.
c.	How often does your husband/partner keep track of what you need to do about your risk for breast cancer?	1	2	3	4	5	Н35с.
d.	How often does your husband/partner change his activities to assist you in your health care?	1	2	3	4	5	H35d.
18.	Has your husband/partner attended individual, fami informed about your risk for breast cancer and what (1) Yes   (5) No.	can be	oup sess done?	ions to	become	÷	Н36.
19.	How much contact has your husband/partner had we concerning your risk for breast cancer.	th medic	cal pers	onnel			Н37.
	Very Little or None 1 2 3 4 5	6	A le 7	ot			
20.	Do you feel your husband/partner is adequately infocancer and what can be done about it?	rmed co	ncernin	g your 1	risk for	breast	Н38.
	Not at All 1 2 3 4 5	6	Very I	Much			
21.	To what extent are you satisfied with your husband/health care?	partner's	s involv	ement i	n your		Н39.
	Not at All 1 2 3 4 5	6	Very I	Much			

## **MOOD SECTION**

1.	blue,			
		(1) □ Yes	(5) □ No	
	1 <b>a</b> .	If yes, there	was such a two-week period, did your work or relationships suffer	? I14a.
		(1) ☐ Yes	(5) □ No	
	1b.	If <b>yes</b> , there y	was such a two-week period, did you get counseling or by?	I14b.
		(1) ☐ Yes	(5) □ No	
	1c.	If <b>yes</b> , there for this condi	was such a two-week period, did you get medication ition?	I14c.
		(1) ☐ Yes	(5) □ No	
2.	felt s	ad, blue, or depr ies or things you	ns, have you had two weeks or more when nearly every day you ressed or in which you lost all interest in things like work or u usually liked to do for fun?  (5)   No	I12.
	2a.	If yes, there	was such a two-week period in the past 6 months, did relationships suffer?	I12a.
		(1) ☐ Yes	•	
	2b.		was such a two-week period in the past 6 months, did you get r psychotherapy?	I12b.
		(1) □ Yes	(5) □ No	
	2c.		was such a two-week period in the past 6 months, did you get cation for this condition?	I12c.
		(1) ☐ Yes	(5) □ No	
3.		ou <b>currently</b> reactional problem	eceiving counseling, psychotherapy or medication for depression as?	I13.
		(1) ☐ Yes	(5) □ No	

### **STRAIN SECTION**

LISTED BELOW ARE SOME SYMPTOMS OF STRAIN THAT PEOPLE SOMETIMES HAVE. Please Read Each One Carefully And Check The Answer Which Best Reflects How Much That Symptom Has Bothered You During the <u>Past Three Months</u>.

		l Not at all	2 A little	3 Quite a bit	4 Extremely
1.	Suddenly scared for no reason				
2.	Feeling fearful				
3.	Faintness, dizziness, or weakness				
4.	Nervousness or shakiness inside				
5.	Heart pounding or racing				
6.	Trembling				
7.	Feeling tense or keyed up				
8.	Headaches				
9.	Spells of terror or panic				
10.	Feeling restless, can't sit still				
11.	Feeling low in energyslowed down				
12.	Blaming yourself for things	;			
13.	Crying easily				
14.	Loss of sexual interest or pleasure				
15.	Poor appetite				
16.	Difficulty falling asleep, staying asleep				
17.	Feeling hopeless about the future				
18.	Feeling blue				
19.	Feeling lonely				
20.	Feeling trapped or caught				
21.	Worrying too much about things				
22.	Feeling no interest in things				
23.	Thoughts of ending your life				
24.	Feeling everything is an effort				
1	Feelings of worthlessness				

### **COPING SECTION**

1. Sometimes people can find unexpected benefits in difficulties. We are interested in the ways in which you might have made positive use of your risk for breast cancer. For each of the statements below, indicate the degree to which your life is affected <u>positively</u> by your risk of breast cancer.

		Not At All	A Very Small Degree	A Small Degree	A Moderate Degree	A Great Degree	A Very Great Degree	
a.	My priorities about what is important in life.	1	2	3	4	5	6	L6a.
b.	I'm more likely to try to change things which need changing.	1	2	3	4	5	6	L6b.
c.	An appreciation for the value of my own life.	1	2	3	4	5	6	L6c.
d.	A feeling of self-reliance.	1	2	3	4	5	6	L6d.
e.	A better understanding of spiritual matters.	1	2	3	4	5	6	L6e.
f.	Knowing that I can count on people in times of troubles.	1	2	3	4	5	6	L6f.
g.	A sense of closeness with others.	1	2	3	4	5	6	L6g.
h.	Knowing I can handle difficulties.	1	2	3	4	5	6	L6h.
i	A willingness to express my emotions.	1	2	3	4	5	6	L6i.
j.	Being able to accept the way things work out.	1	2	3	4	5	6	L6j.
k.	Appreciating each day.	1	2	3	4	5	6	L6k.
l.	Having compassion for others.	1	2	3	4	5	6	L61.
m.	I'm able to do better things with my life.	1	2	3	4	5	6	L6m.
n.	New opportunities are available which wouldn't have been otherwise.	1	2	3	4	5	6	L6n.

2. This set of questions deals with ways you've been coping with the stress in your life that comes with being at risk for breast cancer. There are many ways people try to deal with problems. Obviously, different people deal with things in different ways, but we are interested in how you've tried to deal with it. Each item says something about a particular way of coping. We 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 it seems to be working but just whether or not you're doing it. Use these response choices below and try not to let one answer influence another. Make your answers as true FOR YOU as you can.

		T	T	<del></del>	
		I haven't been doing this at all I	I've been doing this a little bit 2	I've been doing this some 3	I've been doing this a lot 4
a.	I've been turning to work or other activities to take my mind off things.	1	2	3	4
b.	I've been concentrating my efforts on doing something about my situation.	1	2	3	4
с.	I've been saying to myself "this isn't possible."	1	2	3	4
d.	I've been using alcohol or other drugs to make myself feel better.	1	2	3	4
e.	I've been getting emotional support from others.	1	2	3	4
f.	I've been giving up trying to deal with it.	1	2	3	4
g.	I've been taking action to try to make the situation better.	1	2	3	4
h.	I've been refusing to believe that it is possible that I have the gene.	1	2 ·	3	4
i.	I've been saying things to let my unpleasant feelings escape.	1	2	3	4
j.	I've been using alcohol or other drugs to help me get through it.	1	2	3	4
k.	I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4
l.	I've been trying to come up with a strategy about what to do.	1	2	3	4
m.		1	2	3	4

	I haven't been doing this at all 1	I've been doing this a little bit 2	I've been doing this some 3	I've been doing this a lot 4
n. I've been giving up the attempt to cope.	1	2	3	4
o. I've been accepting the possibility that I might have the gene.	1	2	3	4
p. I've been expressing my negative feelings.	1	2	3	4
q. I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4
r. I've been learning to live with the possibility that I might have the gene.	1	2	3	4
s. I've been thinking hard about what steps to take.	1	2	3	4
t. I've been praying or meditating.	1	2	3	4
u. I've been making fun of the situation.	1	2	3	4

3. The following items are to be answered only by those women who are <u>married or living with a partner</u>.

□ Not married or living with a partner

□ Skip to Last Section on page 15, Background Data)

		I haven't been doing this at all I	I've been doing this a little bit 2	I've been doing this some 3	I've been doing this a lot 4
a.	I've been denying or hiding my anger around my husband/partner.	1	2	3	4
b.	I've been denying or hiding my worries around my husband/partner.	1	2	3	4
c.	I've been avoiding talking about my problems around my husband/partner.	1	2	3	4
d.	I've acted more positive around my husband/partner than I feel.	1	2	3	4

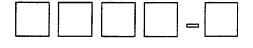
### **BACKGROUND DATA**

These are a few questions about your religious background, that we forgot to ask on the original questionnaire.

1.	Religio	n:	Catholic Jewish Muslim	(1)	Protestant Buddhist Other None	(4) □ (5) □ (6) □ (7) □	A3.
	1 <b>a</b> .	a. How often do you attend religious services?  (1) (5)  □ Less Often Than Once a Month □ A Few Times A Month or More					A3a.
	1b.	How important are religious and spiritual beliefs in your life?					
		Not at All	2	3	Ver	ry Important 5	

Once Again, We thank you for all of your valued participation in this study.









## WOMEN'S HEALTH STUDY

Pre-Results Questionnaire

TODAY'S DATE
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П	

#### PRE-RESULTS ASSESSMENT - U/R

This questionnaire, from the Women's Health Study being conducted by the University of Michigan Medical Center and the University of Pennsylvania Cancer Center, is being given to women who are now being offered the opportunity to learn whether have the altered gene associated with risk for early breast cancer. Again, we remind you that many of the questions are new. Some of them were asked in the first questionnaire you completed. We are asking them again because we are interested in feelings and attitudes which may change over time. THANK YOU VERY MUCH!

## **GENETIC TESTING-SECTION 1**

1.	Have you met with anyone to have	genetic counseling?
----	----------------------------------	---------------------

B24.

□ No

2. Has any member of your family met with someone to have genetic counseling?

B25.

□ No

3. Do you believe you have the altered gene that increases the risk of breast cancer?

B72.

es 🗆 No

4. How confident are you in this belief?

Not At A Confider					Co	Very onfident
1	2	3	4	5	6	7

B73.

5. As the opportunity to get testing has approached, has your interest in getting results changed?

B74.

Decreased	Decreased	N o	Increased	Increased
Very Much	Slightly	Change	Slightly	Very Much
1	2	3	4	5

## **PERSONAL ATTITUDES SECTION**

1. For each of these statements, please indicate the extent to which you agree or disagree by circling the appropriate number. There are no right or wrong answers. We are only interested in your opinions.

		Strong Disagr				rongly Agree	ı
a.	If you don't have your health, you don't have anything.	1	2	3	4	5	L5a.
b.	There are many things I care about more than my health.	1	2	3	4	5	L5b.
c.	Good health is of only minor importance in a happy life.	1	2	3	4	5	L5c.
d.	There is nothing more important than good health.	1	2	3	4	5	L5d.
e.	In uncertain times, I usually expect the best.	1	2	3	4	5	E1.
f.	It's easy for me to relax.	1	2	3	4	5	E2.
g.	If something can go wrong for me, it will.	1	2	3	4	5	E3.
h.	I always look on the bright side of things.	1	2	3	4	5	E4.
i.	I'm always optimistic about my future.	1	2	3	4	5	E5.
<u>j.</u>	I enjoy my friends a lot.	1	2	3	4	5	E6.
k.	It's important for me to keep busy.	1	2	3	4	5	E7.
1.	I hardly ever expect things to go my way.	1	2	3	4	5	E8.
m.	Things never work out the way I want them to.	1	2	3	4	5	E9.
n.	I don't get upset too easily.	1	2	3	4	5	E10.
0.	I'm a believer in the idea that "every cloud has a silver lining."	1	2	3	4	5	E11.
p.	I rarely count on good things happening to me.	1	2	3	4	5	E12.

# **GENETIC TESTING-SECTION 2**

Are ye (Plea	ou planning to ta se check <u>one</u>	ke the genetic response).	test to learn if y	our cancer is th	ne type that runs in f	amilies?
a	I will <u>c</u>	<u>lefinitely</u> take t	he test <u>immedia</u>	tely when it be	comes available.	
b	I will <u>c</u>	<u>lefinitely</u> take t	he test, but I an	not sure if im	mediately.	
c	I will p	orobably take th	e test immediat	ely when it bec	comes available.	
d	I will ţ	orobably take th	ne test, but not i	mmediately.		
e	I am <u>u</u>	ndecided wheth	ner I will take th	e test		
f	I will p	orobably not tal	ke the test.			
g	I will <u>c</u>	lefinitely not ta	ke the test.			
On the	e following scale hay be at increase	e, indicate how ed risk for brea	distressing it is st cancer becau	for you to kn se of your fami	ow that ily history?	В
	Not At All Distressing				Very Distressing	
	1	2	3	4	5	
	Not At All Distressing				Very Distressing	
	1	2	3	4	5	
How o	distressed do you (just before you i	expect to be receive results)	when you actua?	lly get tested f	or the BRCA-1  Very Distressed	В
	1	2	3	4	5	
How o	distressed would	you be if you	took the test an	d found that yo	ou had the	В
BRCA	A-1 gene?	-		·		ъ
BRCA	Not At All Distressed				Very Distressed	, <b>0</b>

		Not At All  1 2  often do you worry about oping breast cancer?  hat extent do these worries ere with your every day life often do you worry about				Ver Distre			
		1	2	3		4		5	
	Overa	ll, to what exte	nt do you welcon	ne the op	portun	ity to be	tested f	or the B	RCA-1
								Very Much	
		1	2	3		4		5	
				Not A	t All		All Th	e Time	
	How o	often do you w ping breast car	orry about ncer?	1	2	3	4	5	
				1	2	3	4	5	
	having	the altered ger	the altered gene carrying risk		2	3	4	5	
_	To wh		ese worries you is altered gene	1	2	3	4	5	

12.	When was the last time you had a mammography? (99)								
	MonthYear	ry.							
13.	How many times have you conducted a breast self-examinations (BSE) in the past six months?	В33.							
	times (99)  This question does not apply because of surgery.								

B32.

12.

14.	How	confident are	you th	at you will	perforn	n breast s	elf exam	ination (BSE)	
	14a.	as freque	ently a	s needed?	(9) 🗆 ]	Does Not	Apply 1	Because of Surgery	B34a.
		Not at All	2	3	4	5	6 V	Very Much So 7	
	14b.	as carefu	ılly an	d compet	•			ly Because of Surgery	B34b.
		Not at All	2	3	4			Very Much So	

For each of the following areas of your life, you will be asked to make <u>two</u> ratings. First, indicate how much these decisions have been affected by <u>the possibility that you have an increased risk for breast cancer</u> (based on your family history). Second, how much would these decisions be affected by the <u>results of genetic testing</u>?

1	2	2		_
1	2	3	4	5
Not at all affe	cted			Very much affected

					ed by a ast can			uld be				
15.	Decisions about having children	1	2	3	4	5	1	2	3	4	5	B35a B35b
16.	Decisions about form of birth control	1	2	3	4	5	1	2	3	4	5	B36a B36b
17.	Decisions about which steps to take to prevent the recurrence of breast cancer	1	2	3	4	5	1	2	3	4	5	B37a B37b
18.	Decisions about work and career	1	2	3	4	5	1	2	3	4	5	B38a B38b
19.	Decisions about savings and financial planning	1	2	3	4	5	1	2	3	4	5	B39a B39b
20.	Decisions about plans for the future	1	2	3	4	5	1	2	3	4	5	B40a B40b

21.	Answer	the	following	question	only	if	vou	have	daughters.	

☐ Does Not Apply
(Skip to Next Section, Life Events)

B41.

					ed by l reast c	-		uld be ults of				
a-b.	Plans for your daughter's future	1	2	3	4	5	1	2	3	4	5	B42 a/b

22. Do you feel you have enough information about breast cancer to make any decisions that might be necessary?

Not At All						Very Much
1	2	3	4	5	6	7

B43.

23. Do you feel you are adequately informed about the benefits and drawbacks of genetic testing for risk of breast cancer?

Not At All						Very Much
1	2	3	4	5	6	7

B44.

24. Do you feel you are adequately informed about what you could do to reduce your risk of breast cancer if you had the altered BRCA1 gene?

Not At All						Very Much
1	2	3	4	5	6	7

B45.

B46.

25. Do you feel you are adequately informed about the benefits and drawbacks of each option available to women who have the altered BRCA1 gene?

Not At All						Very Much
1	2	3	4	5	6	7

6

26. Do you feel you are adequately informed about what it would mean for your children if you had the altered BRCA1 gene?

Not At All						Very Much
1	2	3	4	5	6	7

B47.

B48a.

#### 27. How confident are you that you:

a. Will make the best decision in deciding whether to be tested for BRCA1, the altered gene associated with risk of breast cancer?

Not At All						Very Much
1	2	3	4	5	6	7

b. Would cope effectively with a finding that you had the altered BRCA1 gene?

Not At All						Very Much	В48ь.
1	2	3	4	5	6	7	

c. Would make the best decision concerning your options if you were found to have the altered BRCA1 gene?

Not At All						Very Much	B48c.
1	2	3	4	5	6	7	

d. Would be able to follow through and cope effectively over the long haul if you were found to have the altered BRCA1 gene?

Not At All						Very Much	B48d.
1	2	3	4	5	6	7	

## **RELATIONSHIPS SECTION**

1.	Is the	ere anyone in your life with whom you can nout holding back?	share	your mo	st private feelings	C21.
	WIL	(1) ☐ Yes (5) ☐ No				C21.
2.		arried, can you share your most private feeling back?  (1) $\square$ Yes (5) $\square$ No		vith your	husband without	C21a.
3.	If may	arried, is there anyone besides your husban most private feelings without holding back (1) \(\sum Yes\) (5) \(\sum No	:?	whom y	ou can share	C21b.
1.	Have ( <b>Ch</b>	LIFE EVENTS  e any of the following events happened to y  eck All That Apply)			<del></del>	D1(a-m)
a.		You retired, were fired, or laid off from work.	g.		A close family member ill or injured.	was seriously
b.		You were unemployed and looking for work.	h.		You had a marital separa divorce.	ation or
C.		Your spouse retired, was fired, or laid off from work.	i.		You had serious trouble or close friends.	s with relative
d		Your spouse was unemployed and looking for work.	j.		Your spouse had trouble difficulties with relatives	
e.		You had problems with the police or court.	k.		friends.  A close family member	died.
f.		You got into serious financial difficulties.	l. m.		A close friend or relative You were seriously ill o	e died.

#### **MARRIAGE SECTION**

E-a.

H3.

H4.

H6.

H7.

H12.

H15.

The following questions apply to persons who are <u>married or living with</u> a partner. If you are not married or living with a partner, check the appropriate box and please skip to the Next Section, MOOD.

Most persons have disagreements in their relationships. Please check the appropriate

Not married or living with a partner  $\Box$ 

box to your	o indicate the extent of ag partner <b>DURING THE</b>	greement PAST N	or disagi MONTH	reement e , regardi	experienc ng.	ed betwe	en you an
		6	5	4	3	2	1
· •		Always Agree	Almost Always Agree	Occa- sionally Disagree	Fre- quently Disagree	Almost Always Disagree	Always Disagree
1.	Religious matters						
2.	Demonstration of affection						
3.	Sex relations						

Conventionality (correct or

proper behavior)

Career decisions

5. Making major decisions

		1	2	3	4	5	6	
		All of the time	Most of the time	More often than most	Occa- sionally	Rarely	Never	
7.	How often do you discuss or have you considered divorce, separation, or terminating your relationship?							<b>H</b> 1
8.	Do you ever regret that you married (or are living together)?							Н2
9.	How often do you and your husband/partner quarrel?							Н2
10.	How often do you and your husband/partner "get on each other's nerves?"							Н2

| Some of Very few of Them | Some of Them | None of Them | 
H24.

How often would you say the following events occur between you and your husband/partner?

	[	1	2	3	4	5	6
		Never	Less than once a month	About twice a month	About twice a week	Once a day	More Often
12.	Have a stimulating exchange of ideas						
13.	Calmly discuss something						
14.	Work together on a project						

H25.

H27.

H28.

15. Considering only the positive feelings you have toward your husband/partner, and ignoring the negative ones, please rate how positive these feelings are:

H33.

Not A Posi								remely sitive	
1	2	3	4	5	6	7	8	9	10

16. Considering only the negative feelings you have toward your husband/partner, and ignoring the positive ones, please rate how negative these feelings are:

H34.

Not At All Negative									remely gative
1	2	3	4	5	6	7	8	9	10

The following questions concern your husband's involvement in your health care. 17.

						Never				Very Often	
a.	How often does your your appointments wi			o with y	you to	1	2	3	4	5	H35a.
b.	How often does your doctor or other medica breast cancer?					1	2	3	4	5	Н35Ь.
c.	How often does your what you need to do a					1	2	3	4	5	Н35с.
d.	How often does your lactivities to assist you				is	1	2	3	4	5	H35d.
18.	Has your husband/ informed about you	partner attuur risk for	ended in breast ca Yes [	ancer ar	al, famil nd what 5 No □	can be o	up sessi lone?	ions to l	become		Н36.
19.	How much contact concerning your ris	has your h sk for brea	nusband st cance	/partner r?	had wit	th medic	cal perso	onnel			Н37.
	Very Little or None 1	2	3	4	5	6	A le 7	ot			
20.	Do you feel your he cancer and what can	usband/par n be done	rtner is a about it?	adequate?	ely infor	med co	ncernin	g your r	isk for l	breast	Н38.
	Not at All	2	3	4	5	6	Very N	Much			
21.	To what extent are health care?	you satisfi	ied with	your hi	usband/p	partner's	involv	ement i	n your		Н39.
	Not at All	2	3	4	5	6	Very N	Much			

## **MOOD SECTION**

1.	blue, o	you <b>ever in your lifetime</b> had two weeks or more when nearly every day you felt or depressed or in which you lost all interest in things like work or hobbies or things y liked to do for fun?	sad, you
	•	1 5 □ Yes □ No	I14
	1a.	If yes, there was such a two-week period, did your work or relationships suffer?  1 5  ☐ Yes ☐ No	I14a.
	1b.	If yes, there was such a two-week period, did you get counseling or psychotherapy?  1 5  No	I14b.
	1c.	If yes, there was such a two-week period, did you get medication for this condition?  1 5  □ Yes □ No	I14c.
2.	felt sa	past 6 months, have you had two weeks or more when nearly every day you d, blue, or depressed or in which you lost all interest in things like work or es or things you usually liked to do for fun?  1 5  Yes  No	I12.
	2a.	If yes, there was such a two-week period in the past 6 months, did your work or relationships suffer?  1 5  Yes No	I12a.
	2b.	If yes, there was such a two-week period in the past 6 months, did you get counseling or psychotherapy?  1 5  Yes No	I12b.
	2c.	If yes, there was such a two-week period in the past 6 months, did you get medication for this condition?  1 5  □ Yes □ No	I12c.
3.	Are you	ou currently receiving counseling, psychotherapy or medication for depression of the problems?  1 5  Yes  No	I13.

## **SYMPTOMS OF STRAIN SECTION**

LISTED BELOW ARE SOME SYMPTOMS OF STRAIN THAT PEOPLE SOMETIMES HAVE. Please Read Each One Carefully And Check The Answer Which Best Reflects How Much That Symptom Has Bothered You During the <u>Past Three Months</u>.

		l Not at all	2 _A little	3 Quite a bit	4 Extremely
1.	Suddenly scared for no reason			2	<u> 2300 entery</u>
2.	Feeling fearful				
3.	Faintness, dizziness, or weakness				
4.	Nervousness or shakiness inside				
5.	Heart pounding or racing				
6.	Trembling				
7.	Feeling tense or keyed up				
8.	Headaches				
9.	Spells of terror or panic				
10.	Feeling restless, can't sit still				
11.	Feeling low in energyslowed down				
12.	Blaming yourself for things				
13.	Crying easily				
14.	Loss of sexual interest or pleasure				
15.	Poor appetite				
16.	Difficulty falling asleep, staying asleep				
17.	Feeling hopeless about the future				
18.	Feeling blue				
19.	Feeling lonely				
20.	Feeling trapped or caught				
21.	Worrying too much about things				
22.	Feeling no interest in things				
23.	Thoughts of ending your life				
24.	Feeling everything is an effort				
25.	Feelings of worthlessness				

## **COPING SECTION**

1. Sometimes people can find unexpected benefits in difficulties. We are interested in the ways in which you might have made positive use of your risk for breast cancer. For each of the statements below, indicate the degree to which your life is affected <u>positively</u> by your risk of breast cancer.

		Not At All	A Very Small Degree	A Small Degree	A Moderate Degree	A Great Degree	A Very Great Degree	
a.	My priorities about what is important in life.	1	2	3	4	5	6	L6a.
b.	I'm more likely to try to change things which need changing.	1	2	3	4	5	6	L6b.
c.	An appreciation for the value of my own life.	1	2	3	4	5	6	L6c.
d.	A feeling of self-reliance.	1	2	3	4	5	6	L6d.
e.	A better understanding of spiritual matters.	1	2	3	4	5	6	L6e.
f.	Knowing that I can count on people in times of troubles.	1	2	3	4	5	6	L6f.
g.	A sense of closeness with others.	1	2	3	4	5	6	L6g.
h.	Knowing I can handle difficulties.	1	2	3	4	5	6	L6h.
i	A willingness to express my emotions.	1	2	3	4	5	6	L6i.
j.	Being able to accept the way things work out.	1	2	3	4	5	6	L6j.
k.	Appreciating each day.	1	2	3	4	5	6	L6k.
1.	Having compassion for others.	1	2	3	4	5	6	L61.
m.	I'm able to do better things with my life.	1	2	3	4	5	6	L6m.
n.	New opportunities are available which wouldn't have been otherwise.	1	2	3	4	5	6	L6n.

2. This set of questions deals with ways you've been coping with the stress in your life that comes with being at risk for breast cancer. There are many ways people try to deal with problems. Obviously, different people deal with things in different ways, but we are interested in how you've tried to deal with it. Each item says something about a particular way of coping. We 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 it seems to be working but just whether or not you're doing it. Use these response choices below and try not to let one answer influence another. Make your answers as true FOR YOU as you can.

		I haven't been doing this at all I	I've been doing this a little bit 2	I've been doing this some 3	I've been doing this a lot 4
a.	I've been turning to work or other activities to take my mind off things.	1	2	3	4
). 	I've been concentrating my efforts on doing something about my situation.	1	2	3	4
;.	I've been saying to myself "this isn't possible."	1	2	3	4
l.	I've been using alcohol or other drugs to make myself feel better.	1	2	3	4
•	I've been getting emotional support from others.	1	2	3	4
•	I've been giving up trying to deal with it.	1	2	3	4
•	I've been taking action to try to make the situation better.	1	2	3	4
•	I've been refusing to believe that it is possible that I have the gene.	1	2	3	4
•	I've been saying things to let my unpleasant feelings escape.	1	2	3	4
	I've been using alcohol or other drugs to help me get through it.	1	2	3	4
	I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4
	I've been trying to come up with a strategy about what to do.	1	2	3	4
n.	I've been getting comfort and understanding from someone.	1	2	3	4

		I haven't been doing this at all 1	I've been doing this a little bit 2	I've been doing this some 3	I've been doing this a lot 4	
n.	I've been giving up the attempt to cope.	1	2	3	4	1
0.	I've been accepting the possibility that I might have the gene.	1	2	3	4	j
p.	I've been expressing my negative feelings.	1	2	3	4	]
q.	I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4	]
r.	I've been learning to live with the possibility that I might have the gene.	1	2	3	4	
S .	I've been thinking hard about what steps to take.	1	2	3	4	]
t.	I've been praying or meditating.	1	2	3	4	]
u.	I've been making fun of the situation.	1	2	3	4	I

3. The following items are to be answered only by those women who are <u>married or living with a partner</u>.

□ Not married or living with a partner

(Skip to Last Section on page 15, Background Data)

		I haven't been doing this at all 1	I've been doing this a little bit 2	I've been doing this some 3	I've been doing this a lot 4	
a.	I've been denying or hiding my anger around my husband/partner.	1	2	3	4	L8a.
b.	I've been denying or hiding my worries around my husband/partner.	1	2	3	4	L8b.
c.	I've been avoiding talking about my problems around my husband/partner.	1	2	3	4	L8c.
d.	I've acted more positive around my husband/partner than I feel.	1	2	3	4	L8d.

#### **BACKGROUND DATA**

These are a few questions about your religious background, that we forgot to ask on the original questionnaire.

1.	Religion	<b>:</b>	Catholic Jewish Muslim	(1)	Protestant Buddhist Other None	(4) □ (5) □ (6) □ (7) □	A3.
	1a.	How often do yo (1) ☐ Less Often Th	•	(5)	)	A Month or More	A3a.
	1b.	How important a	are religious a	and spiritual t	peliefs in your li	fe?	A3b.
		Not at All	2	3	Ver	ry Important 5	

Once again, We thank you for all of your valued participation in this study.





## WOMEN'S HEALTH STUDY

Sister Questionnaire

Today's	Date	

ID		
117	TI	
	w	_

## SISTER QUESTIONNAIRE

HEAL	TH	<b>SECTION</b>

		<u>HE</u>	ALTH SI	<u>ECTION</u>	·	
1.	Have y	ou ever been diagnosed with	Breast cancer?	(1)  Yes	(5) No	B1u.
2.	Have y	ou ever been diagnosed with (	Ovarian cancer?	(1) \( \sum \) Yes	(5) No	B5.
	arian c	er the following question ancer. e never been diagnosed v				n breast
3.	When	were you first diagnosed with	breast cancer?			В1.
		MonthYear		Applicable		
4.	When	were you first diagnosed with  MonthYear		Applicable		B5a.
5	Цомал	ou received any of the follow	ing treatments?			
5.	nave y	Chemotherapy	(1) $\square$ Yes	(5) No		B4a.
		Radiation	(1) ☐ Yes	•		B4b.
		Surgery		(5) No		B4c.
6.	Have y	ou ever had any of the follow	ving surgical pro	cedures?		
	6a.	Lumpectomy (Removal of				B6a.
	ou.	$(1) \square \text{ Yes}  (5) \square \text{ No}$			Year	B6a2.
	6b.	Oophorectomy (Removal o	of ovaries)			B6b.
		(1) ☐ Yes (5) ☐ No	If yes, when?	Month	_ Year	B6b2.
	6c.	Unilateral mastectomy (F	Removal of one	breast)	•	B6c.
	00.	$(1) \square \text{ Yes } (5) \square \text{ No}$		Month	_ Year	B6c2.
	6d.	Hysterectomy (Removal	of uterus)			B6d.
		(1) ☐ Yes (5) ☐ No		Month	_ Year	B6d2.
	6e.	Bilateral mastectomy (Re	emoval of both	breasts)		B6e.
		(1) ☐ Yes (5) ☐ No		Month	_ Year	B6e2.

7.	Do you currer		ourself in No	remission? (3)   I Dor	ı't Know			В3.
8.	Have you eve		ence of bre	ast or ovarian (3)   I Dor	cancer?			B100.
9.	Before your d to develop br	iagnosis of breast cancer,	east cance compared	r, how likely to <b>the avera</b>	did you thinge woman	nk you were 1? (Please c	rcle one)	В7.
		Much Less Likely			M	luch More Likely		
		1	2	3	4	5		
10.	Before your do	liagnosis of breast cancer,	reast cance compared	r, how likely to the <b>wome</b>	did you thi	nk you were family? (Pl	ease circle one)	В8.
		Much Less Likely			N	luch More Likely	<b>71.</b>	
		1	2	3	4	5	Skip to Question 13	
11.	How likely d (Please ci	id you think y rcle one)  Much Less Likely		develop breas		ompared to th  Iuch More Likely	e average woman?	В7а.
		1	2	3	4	5		
12.	How likely d	id you think y	ou are to e	develop breas	st cancer, co	ompared to <b>th</b>	e women	В8а.
		Much Less Likely	3		N	luch More Likely		
		1	2	3	4	5		
13.	When was the	e last time you	ı had a ma	mmography?				B32.
	N	Ionth		☐ This ques	tion does n	ot apply beca	use of surgery.	
14.	How many ti past six mon	mes have you ths?	conducted	l a breast self-	-examinatio	on (BSE) in the	2	В33.
		times		☐ This que: (-8)	stion does r	not apply beca	use of surgery.	

15.	In gen	eral, wou	ld you say your health is:				I1.		
	☐ Exc	cellent	☐ Very Good (2)	☐ Good	☐ Fair (4)	□ Poor (5)			
16.	Compared to one year ago, how would you rate your health in general now?  (Please Check one only)  (1)  Much better now than one year ago  (2)  Somewhat better now than one year ago  (3)  About the same as one year ago  (4)  Somewhat worse now than one year ago  (5)  Much worse than one year ago								
			FAMILY HIS	STORY SE	<u>CTION</u>				
	next se	_	estions, we are interested	d in learning ab	out your family	y's experienc	ce with		
1.	Have	any of yo	ur relatives been diagnosed v	with breast cancer?			B91.		
	(	(1) 🗆 Yes	(5) 🗆 No (3) 🗀 I	Don't Know					
2.	If Yes	how mark? (How i	any of the following relative many relatives for each categ	s been affected by ory where applicab	(diagnosed with)	breast			
		E	Relative:	How Many?					
		a. S	Sister(s)				B92a.		
	•	b. N	Mother				B92b.		
		c. (	Grandmother(s) Maternal			1	B92c1.		
		d. C	Grandmother(s)Paternal			3	B92c2.		
		e. A	Aunt(s) Maternal			!	B92d1.		
		f.	Aunt(s) Paternal			!	B92d2.		
	L								

B92e1.

B92e2.

B92f.

B92g.

Cousin(s) Maternal

Cousin(s) Paternal

Wife

Daughter(s)

g.

h.

i.

How o	r bre	east cancer b	for you to kno because of the	ow tha	t women in yo nily history?	our famil	ly may be	at increased	
		Not At A Distressi						Very Distressing	
		1	2		3		4	5	
									e
					Yes	5	No	Not Applicabl	/0
	T						سر	0	
a.	-	other			1		5	9	B93a.
a. b.	-	other andmother(	(s)		1		5	9	B93a.
	Gr		(s)				5	9	B93a.
b.	Gr	andmother(	(s)		1		5	9	B93a. B93b B93c.
b.	Gr Au	randmother( unt(s) ousin(s)	(s)		1		5	9	B93a.  B93b  B93c.  B93d
b. c.	Gr Au Co	randmother( unt(s) ousin(s)	(s)		1 1		5 5 5	9 9	

(3) No Opinion

(1) Yes

(5) 🗆 No

8. How often do you discuss your family's risk for breast cancer with your sister who gave us your name?

B75.

Never	Rarely	Sometimes	Often
1	2	3	4

8a. If you have these discussions, who generally initiates them?

B75a.

You	Your Sister	Equally	No discussions
1	2	3	4

8b. How satisfied are you with these discussions?

B75b.

No	ot At All	A Little	Somewhat	A Great Deal	No discussions
	1	2	3	4	5

9. How often does **your sister** seek your support concerning the risk of breast cancer to women in your family?

B49a.

Never	Rarely	Sometimes	Often
1	2	3	4

10. How much of a burden is this on you?

B50.

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

## **GENETIC TESTING SECTION**

Now, we have some questions about breast cancer diagnosis, treatment, and genetic testing.

1. We would like to know how much you have been informed about breast cancer. To what extent do you agree with the following statements?

		Strongly Disagree				rongly Igree	I Don't Know
a	Mammography is effective in the early detection of breast cancer in women.	1	2	3	4	5	9

B20a.

		Strongly Strongly Disagree Agree				I Don't Know		
b.	Breast cancer that is detected early is curable.	1	2	3	4	5	9	B20b.
c.	Mammography can detect lumps that cannot be felt by a woman or by her doctor.	1	2	3	4	5	9	В20с.
d.	If more women went for breast screening, there would be fewer deaths from breast cancer.	1	2	3	4	5	9	B20d.
e.	If a lump is found in a woman's breast, it is usually too late to do anything about it.	1	2	3	4	5	9	B20f.
f.	There are so many things that could happen to someone's health that it is pointless for a woman to worry about breast cancer.	1	2	3	4	5	9	B20i.

There is a test now available that will allow individuals to learn whether they have the altered gene which conveys an increased risk for developing breast cancer.

2. Were you aware that women are being offered the opportunity to take this test?

B77a.

B95a.

B95b.

B95c.

B95d.

B95e.

B95f.

B95g.

B95h.

(1) ☐ Yes (5) ☐ No

3. Do you discuss **genetic testing for breast cancer** susceptibility with any of the following women in your family? (Circle *Not Applicable* if you do not have any living relatives in that category.)

		Yes	N o	Not Applicable
a.	Sister(s)	1	5	9
b.	Mother	1	5	9
c.	Grandmother(s)	1	5	9
d.	Aunt(s)	1	5	9
e.	Cousin(s)	1	5	9
f.	Wife	1	5	9
f.	Daughter(s)	1	5	9
g.	Other women family members	1	5	9

4. Compared to how often you now talk to the women in your family about **genetic testing** for breast cancer, how much would you prefer to talk to them about this topic?

B96.

A Lot Less	A Little Less	Same Amount	A Little More	A Lot More
1	2	3	4	5

5. Do you wish you had more information about genetic te	esting
--	--------

B98.

(1)	$\Box$	Yes
111	1 1	1 60

6. How often do you discuss genetic testing for breast cancer with your sister?

B51a.

Never	Rarely	Sometimes	Often	
1	2	3	4	

6a. If you have these discussions, who generally initiates them?

B52a.

You	Your Sister	Equally	No discussions
1	2	3	4

6b. How satisfied are you with these discussions?

B53.

Not At All	A Little	Somewhat	A Great Deal	No discussions
1	2	3	4	5

7.	What are your plans concerning this genetic test at the present time?
	(Please check <u>one</u> response).

B15c.

(1)	I will	definitely	take	the	test s	soon.
-----	--------	------------	------	-----	--------	-------

(2)	I will definitely	take the	test	but I	am	not sure	when.
(2)	i wili <u>definitely</u>	iake ille	iesi,	Dut 1	ain	not sure	WIICII.

\-	Please check all that apply).	
(1)	To make decisions about family planning.	
(2)	To find out the risk that may be transmitted to my children.	
(3)	To find out about the risk to a daughter who is too young to be tested.	
(4)	Family members want me to get testing.	
(5)	I just want to know whether I have the altered gene.	
(6)	I am worried about my own risk for cancer.	
(7)	Other (describe)	
If no	you do not think you will probably or definitely take the test, what are your reasons for ot doing so? (Please check all that apply).	B17a.
(1)	I am happier not knowing.	
	I am happier not knowing.  I do not see any reason for learning if I have the altered gene.	
(2)	Continuing if I have the altered game	
(2)	I do not see any reason for learning if I have the altered gene.	
(2) (3) (4)	I do not see any reason for learning if I have the altered gene.  It would be too upsetting to learn that I have the altered gene.	
(2) (3) (4) (5)	I do not see any reason for learning if I have the altered gene.  It would be too upsetting to learn that I have the altered gene.  I am too worried about women in my family.	
(2) (3) (4) (5)	I do not see any reason for learning if I have the altered gene.  It would be too upsetting to learn that I have the altered gene.  I am too worried about women in my family.  I believe I already know whether I have the altered gene.	
(2) (3) (4) (5) (6)	I do not see any reason for learning if I have the altered gene.  It would be too upsetting to learn that I have the altered gene.  I am too worried about women in my family.  I believe I already know whether I have the altered gene.  There would not be much I could do if I found out I had the altered gene.	
(2) (3) (4) (5) (6) (7)	I do not see any reason for learning if I have the altered gene.  It would be too upsetting to learn that I have the altered gene.  I am too worried about women in my family.  I believe I already know whether I have the altered gene.  There would not be much I could do if I found out I had the altered gene.  I do not feel able emotionally to deal with testing.	
(2) (3) (4) (5) (6) (7) (8)	I do not see any reason for learning if I have the altered gene.  It would be too upsetting to learn that I have the altered gene.  I am too worried about women in my family.  I believe I already know whether I have the altered gene.  There would not be much I could do if I found out I had the altered gene.  I do not feel able emotionally to deal with testing.  Family members do not want me to get testing.	

Not At All Distressed				Very Distressed
1	2	3	4	5

Overall, how important are the opinions of the following family members in your decision whether to be tested for an alteration in a breast cancer susceptibility gene? (Circle *Not Applicable* if you do not have any relatives in that category.)

		Not At All	A Little	Some- what	A Great Deal	Not Applic- able
a.	Sister(s)'s opinion matters	1	2	3	4	9
b.	Spouse/Partner's opinion matters	1	2	3	4	9
c.	Mother's opinion matters	1	2	3	4	9
d.	Daughter's opinion matters	1	2	3	4	9
e.	Other family member(s)'s opinions matter	1	2	3	4	9

B78a.

В78ь.

B78c.

B78d.

B78e.

How pressured do you feel from the following family members to get tested for the altered gene? (Circle *Not Applicable* if you do not have any relatives in that category.)

		Not At All	A Little	Some- what	A Great Deal	Not Applic- able
a.	Sister(s)	1	2	3	4	9
b.	Spouse/Partner	1	2	3	4	9
c.	Mother	1	2	3	4	9
d.	Daughter	1	2	3	4	9
e.	Other family member(s)	1	2	3	4	9

B79a.

B79b.

B79c.

B79d.

B79e.

How much of a **burden** is it **on you** when the women in your family pressure you to get tested for the altered gene?

B80.

N o	A Little	Some	A Great	Not applicable,
Burden	Burden	Burden	Burden	No Pressure
1	2	3	4	5

14. How distressed would you be if you took the test and found that you **did not** have the altered gene which conveys increased risk of breast cancer?

B70a.

Not At All Distressed				Very Distressed
1	2	3	4	5

15. If you were to take the test and find out that you <u>did not have</u> the altered gene which conveys increased risk for breast cancer, what would you expect your reactions to be?

		Strong Disagre	•			rongly Agree	
a.	I would feel wonderful.	1	2	3	4	5	B81a.
b.	I would feel I had been told what I knew all along.	1	2	3	4	5	B81b.
c.	I would feel relieved.	1	2	3	4	5	B81c.
d.	I would not believe the results.	1	2	3	4	5	B81d.
e.	I would fall apart emotionally.	1	2	3	4	5	B81e.
f.	I would feel guilty.	1	2	3	4	5	B81f.
g.	I would still feel anxious.	1	2	3	4	5	B81g.
h.	I would feel angry.	1	2	3	4	5	B81h.
i.	I would feel prepared for the future.	1	2	3	4	5	B81i.
j.	I would feel I had done all I needed to do.	1	2	3	4	5	B81j.
k.	I would not feel very differently.	1	2	3	4	5	B81k.

16. How distressed would you be if you took the test and found that you **did have** the altered gene which conveys increased risk for breast cancer?

B69a.

Not At All Distressed				Very Distressed
1	2	3	4	5

17. If you were to take the test and find out that you <u>had</u> the altered gene, what would you expect your reactions to be?

		Strong Disagr		Strongly Agree		
a.	I would feel relieved about being more certain.	1	2	3	4	5
b.	I would feel I had been told what I knew all along.	1	2	3	4	5
c.	I would not believe the results.	1	2	3	4	5
d.	I would feel guilty.	. 1	2	3	4	5
e.	I would be depressed.	1	2	3	4	5
f.	I would feel worried about the future.	1	2	3	4	5
g.	I would just fall apart emotionally.	1	2	3	4	5

B82a.

B82b.

B82c.

B82d.

B82e.

B82f.

B82g.

		Strong Disagr	gly ree		St	rongly Agree
h.	I would feel anxious.	1	2	3	4	5
i.	I would feel angry.	1	2	3	4	5
j.	I would not feel very differently.	1	2	3	4	5

B82h.

B82i.

B82j.

		Not A	t All		All Th	e Time	
18.	How often do you worry about having the altered gene associated with risk for breast cancer among women?		2	3	4	5	
19.	To what extent do any worries you have about this genetic alteration interfere with every day life?	1	2	3	4	5	
20.	How often do you worry about women in your family developing breast cancer?	1	2	3	4	5	
21.	How often do you worry about developing cancer yourself?	1	2	3	4	5	
22.	How much do worries about developing cancer interfere with your everyday life?	1	2	3	4	5	

B83.

B84.

B85.

B86.

B87.

How likely do you think it is that you have the altered gene which conveys increased risk for breast cancer in women relatives? (Please circle one)

B88.

	0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
٠	0	1	2	3	4	5	6	7	8	9	10

How much would it affect your health in the future if you had the altered gene which conveys increased risk for breast cancer in women relatives?

B89.

☐ Not at All

(1)

☐ A Little

(2)

☐ Somewhat

(3)

☐ A Great Deal

(4)

☐ I Don't Know

(5)

Overall, what do you think your risk is of developing cancer (or developing cancer again) in the future?

B90.

	0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
ı	0	1	2	3	4	5	6	7	8	9	10

# **SYMPTOMS OF STRAIN SECTION**

Listed Below Are Some Symptoms Of Strain That People Sometimes Have. Please Read Each One Carefully And Check The Answer Which Best Reflects How Much That Symptom Has

Bothered You During the Past Three Months.

Doin	ered You During the <u>P<b>ast Three</b> </u>	Not at all	<u>A little</u>	<u>Quite a bit</u>	<u>Extremely</u>	
1.	Suddenly scared for no reason	1	2	3	4	<b>K</b> 1.
<del>2.</del>	Feeling fearful	1	2	3	4	K2.
3.	Faintness, dizziness, or weakness	1	2	3	4	К3.
<del></del> 4.	Nervousness or shakiness inside	1	2	3	4	K4.
5.	Heart pounding or racing	1	2	3	4	K5.
6.	Trembling	1	2	3	4	K6.
7.	Feeling tense or keyed up	1	2	3	4	K7.
8.	Headaches	1	2	3	4	K8.
9.	Spells of terror or panic	1	2	3	4	К9.
10.	Feeling restless, can't sit still	1	2	3	4	K10.
11.	Feeling low in energyslowed down	1	2	3	4	K11.
12.	Blaming yourself for things	1	2	3	4	K12.
13.	Crying easily	1	2	3	4	K13.
14.	Loss of sexual interest or pleasure	1	2	3	4	K14.
15.	Poor appetite	1	2	3	4	K15.
16.	Difficulty falling asleep, staying asleep	1	2	3	4	K16.
17.	Feeling hopeless about the future	1	2	3	4	K17.
18.	Feeling blue	1	2	3	4	K18.
19.	Feeling lonely	1	2	3	4	K19.
20.	Feeling trapped or caught	1	2	3	4	K20.
21.	Worrying too much about things	1	2	3	4	K21.
22.	Feeling no interest in things	1	2	3	4	K22.
23.	Thoughts of ending your life	1	2	3	4	K23.
24.	Feeling everything is an effort	1	2	3	4	K24.
25.	Feelings of worthlessness	1	2	3	4	K25.

## **FAMILY RELATIONSHIPS SECTION**

1. Please indicate the extent to which each of the following items currently describes the family in which you grew up.

	you grew up.	Strong Disag				rongly Agree	
a.	Planning family activities is difficult because we misunderstand each other.	1	2	3	4	5	M1.
b.	In times of crisis we can turn to each other for support.	1	2	3	4	5	M2.
c.	We cannot talk to each other about the sadness we feel.	1	2	3	4	5	М3.
d.	Individuals are accepted for who they are.	1	2	3	4	5	M4.
e.	We avoid discussing our fears and concerns.	1	2	3	4	5	M5.
f.	We can express feelings to each other.	1	2	3	4	5	Мб.
g.	There are lots of bad feelings in the family.	1	2	3	4	5	М7.
h.	We feel accepted for who we are.	1	2	3	4	5	M8.
i.	Making decisions is a problem for our family.	1	2	3	4	5	М9.
j.	We are able to make decisions about how to solve problems.	1	2	3	4	5	M10.
k.	We don't get along well together.	1	2	3	4	5	M11.
1.	We confide in each other.	1	2	3	4 .	5	M12.
2.	Is there anyone in your life with whom you can share holding back?    Yes  No	e your m	ost priv	ate feel	ings wi	thout	C21.
	2a. Do you have that kind of relationship with  ☐ Yes ☐ No	your sis	ster (wh	o gave	us your	name)?	C21c.
3.	How often do you talk to your sister? (check on Most every day A few times a week A few times a month Once a month Less than once a month Less than once a year Never	e)					C22.

## **BACKGROUND DATA SECTION**

Now, we'd like to know more about you. A1. Year Day \_\_\_ Month Date of Birth 1. A2. Black  $\square$  4  $\square$  1 White Ethnic Background: 2.  $\Box$  5  $\square$  2 Asian Hispanic □ 6 Other □ 3 Native American A3. Protestant  $\square$  4  $\square$  1 Catholic Religion: 3. □ 5 Buddhist Jewish Other □ 6  $\square$  3 Muslim None □ 7 A3a. How often do you attend religious services? 3a. ☐ 5 A Few Times A Month or More ☐ 1 Less Than Once a Month How important are religious and spiritual beliefs in your life? A3b. 3b. Very Important Not at All 5 4 2 3 1 A4. Are you currently (please check one)? 1 Single 4. Married 2 🗆 Not married, but living in a steady, marriage-like relationship Separated 5 Divorced 6 ☐ Widowed If you are currently married, what was the date of your current marriage? A5. 5. Month \_\_\_\_ Year \_\_\_\_ Is this your first marriage? (1)  $\square$  Yes (5)  $\square$  No A5a. 5a. A6. How many children do you have? 6. A6a. Number of children living at home? 6a. A6b. 6b. Number who are under age 6? A6c. Number of Daughters? 6c. A12. (3) Undecided Do you plan to have more children? (1) \( \subseteq \text{Yes} (5) No 7. A12a. If yes, how many more children? 7a.

8.	Are you currently we	orking for pay out	side the home	e?				A7.
	(1) $\square$ Yes	(5) No						
9.	If yes, about how m	any hours per wee	ek are you w	orking	g for pay?			A8.
	Less than 10  (1)	10-20 (2)	21-30		31-40 (4)	41 o	r more  (5)	
10.	What is the highest lev	vel of education y	ou have com	pleted	? (Check o	ne)		A9.
	<ul> <li>1 □ Less than 9th g</li> <li>2 □ Dropped out of</li> <li>3 □ Completed hig</li> <li>4 □ Some college</li> </ul>	f high school	6			ate or	professional training te or professional train	ing
The	following two question	ons are optional,	, but we hop	e tha	t you will p	rovide	this information.	
11.	What is your househo	old's total income	? (Check on	e)				Å10.
	(1) ☐ Less than \$1 (2) ☐ \$10,000 to \$ (3) ☐ \$20,000 to \$	(5) [	\$40,000	to \$49	9,999	(7) (8)	\$60,00 to \$69,999 Greater than \$69,999	
12.	How many people (a	adults and children	n) does this i	ncome	support?			A11.

# THANK YOU VERY MUCH FOR YOUR PARTICIPATION.

1	1 1		1 1		
1 1	1 1	t I		_	





## WOMEN'S HEALTH STUDY

Brother Questionnaire

Today's Date	
--------------	--

ID	

#### **BROTHER QUESTIONNAIRE**

#### **FAMILY HISTORY SECTION**

First, we are interested in learning about your family's experience with breast cancer.

1. Have any of your relatives been diagnosed with breast cancer?

B91.

(1) **Yes** 

(5) No

(3) Don't Know

2. If Yes, how many of the following relatives been affected by (diagnosed with) breast cancer? (Record the number of relatives for each category)

	Relative:	How Many?
a.	Sister(s)	
b.	Mother	
c.	Grandmother(s) Maternal	
d.	Grandmother(s)Paternal	
e.	Aunt(s) Maternal	
f.	Aunt(s) Paternal	
g.	Cousin(s) Maternal	
h.	Cousin(s) Paternal	
i.	Wife	
j.	Daughter(s)	

B92a.

B92b.

B92c1.

B92c2.

B92d1.

B92d2.

B92e1.

B92e2.

B92f.

B92g.

3. Do you think that your family is at an increased risk for breast cancer compared with other families?

B99.

(1) **Yes** 

(5) No

(3)  $\square$  I Don't Know

Not At All Distressing				Very Distressing
1	2	3	4	5

5. Do you discuss your family's **increased risk for breast cancer** with any of the following women in your family? (Circle *Not Applicable* if you do not have any living relatives in that category.)

		Yes	No	Not Applicable	
a.	Mother	1	5	9	B93a.
b.	Grandmother(s)	1	5	9	В93ь.
c.	Aunt(s)	1	5	9	В93с.
d.	Cousin(s)	1	5	9	B93d.
e.	Wife	1	5	9	B93e.
f.	Daughter(s)	1	5	9	B93f.
f.	Other women family members	1	5	9	B93g.

6. Compared to how often you now talk to the women in your family about their **risk for breast cancer**, how much would you prefer to talk to them about this topic?

B94.

A Lot Less	A Little Less	Same Amount	A Little More	A Lot More
1	2	3	4	5

7. Do you wish you had more information about your family's risk of breast cancer?

B97.

(1) **Yes** 

(5) No

(3) No Opinion

8. How often do you discuss your family's risk for breast cancer with your sister?

B75.

Never	Rarely	Sometimes	Often
1	2	3	4

8a. If you have these discussions, who generally initiates them?

B75a.

You	Your Sister	Equally	No discussions
1	2	3	4

8b. How satisfied are you with these discussions?

B75b.

Not At All	A Little	Somewhat	A Great Deal	N o discussions
1	2	3	4	5

9. How often does **your sister** seek your support concerning the risk of breast cancer to women in your family?

B49a.

Never	Rarely	Sometimes	Often
1	2	3	4

10. How much of a burden is this on you?

B50.

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

#### **GENETIC TESTING SECTION**

Now, we have some questions about breast cancer diagnosis, treatment, and genetic testing.

1. We would like to know how much you have been informed about breast cancer. To what extent do you agree with the following statements?

		Strong Disagr				rongly Agree	I Don't Know	
a.	Mammography is effective in the early detection of breast cancer in women.	1	2	3	4	5	9	В2
b.	Breast cancer that is detected early is curable.	1	2	3	4	5	9	В2
c.	Mammography can detect lumps that cannot be felt by a woman or by her doctor.	1	2	3	4	5	9	В2

B20a.

B20b.

B20c.

d.	If more women went for breast screening, there would be fewer deaths from breast cancer.	1	2	3	4	5	9	B20d.
e.	If a lump is found in a woman's breast, it is usually too late to do anything about it.	1	2	3	4	5	9	B20f.
f.	There are so many things that could happen to someone's health that it is pointless for a woman to worry about breast cancer.	1	2	3	4	5	9	B20i.

There is a test now available that will allow individuals to learn whether they have the altered gene which conveys an increased risk for developing breast cancer.

2.	Were you aware that wome	n are being offered the opportunity to take this test?	B77a.
	(1) $\square$ Yes	(5) No	

B77b.

Were you aware that men are being offered the opportunity to take this test?

(5) No

(1) **Yes** 

3.

		Yes	No	Not Applicable	
a.	Sister(s)	1	5	9	В95
b.	Mother	1	5	9	B95
c.	Grandmother(s)	1	5	9	В95
d.	Aunt(s)	1	5	9	B95
e.	Cousin(s)	1	5	9	В95
f.	Wife	1	5	9	В95
f.	Daughter(s)	1	5	9	B95
g.	Other women family members	1	5	9	B95

Compared to how often you now talk to the women in your family about **genetic testing** for breast cancer, how much would you prefer to talk to them about this topic?

B96.

A Lot Less	A Little Less	Same Amount	A Little More	A Lot More
1	2	3	4	5

6. Do you wish you had more information about genetic testing?

B98.

(1) \( \sum \) Yes

(5) No

(3) No Opinion

7. How often do you discuss genetic testing for breast cancer with your sister?

B51a.

Never	Rarely	Sometimes	Often
1	2	3	4

7a. If you have these discussions, who generally initiates them?

B52a.

You	Your Sister	Equally	No discussions	
1	2	3	4	

7b. How satisfied are you with these discussions?

B53.

Not At All	A Little	Somewhat	A Great Deal	No discussions
1	2	3	4	5

8.	What are your plans concerning this genetic test at the present time?
	(Please check one response).

B15c.

(1) I will <u>definitely</u> take the test soon.

(2) I will <u>definitely</u> take the test, but I am not sure when.

(3) I will probably take the test.

(4) I am <u>undecided</u> whether I will take the test.

(5) I will probably not take the test.

(6) I will definitely not take the test.

(*	ase check all that apply).	
(1)	To make decisions about family planning.	
(2)	To find out the risk that may be transmitted to my children.	
(3)	To find out about the risk to a daughter who is too young to be tested.	
(4)	Family members want me to get testing.	
(5)	I just want to know whether I have the altered gene.	
(6)	I am worried about my own risk for cancer.	
(7)	Other (describe)	
If yo	u do not think you will probably or definitely take the test, what are your reasons for doing so? (Please check all that apply).	B17a
(1)	I am happier not knowing.	
(1)	C. 1. CT beautiful altered comp	
	I do not see any reason for learning if I have the altered gene.	
(2)	I do not see any reason for learning if I have the altered gene.  It would be too upsetting to learn that I have the altered gene.	
(2)(3)	I do not see any reason for learning if I have the altered gene.  It would be too upsetting to learn that I have the altered gene.  I am too worried about women in my family.	
(2) (3) (4)	I do not see any reason for learning if I have the altered gene.  It would be too upsetting to learn that I have the altered gene.  I am too worried about women in my family.  I believe I already know whether I have the altered gene.	
(2) (3) (4) (5)	I do not see any reason for learning if I have the altered gene.  It would be too upsetting to learn that I have the altered gene.  I am too worried about women in my family.  I believe I already know whether I have the altered gene.  There would not be much I could do if I found out I had the altered gene.	
(2) (3) (4) (5) (6)	I do not see any reason for learning if I have the altered gene.  It would be too upsetting to learn that I have the altered gene.  I am too worried about women in my family.  I believe I already know whether I have the altered gene.  There would not be much I could do if I found out I had the altered gene.  I do not feel able emotionally to deal with testing.	
(2) (3) (4) (5) (6) (7)	I do not see any reason for learning if I have the altered gene.  It would be too upsetting to learn that I have the altered gene.  I am too worried about women in my family.  I believe I already know whether I have the altered gene.  There would not be much I could do if I found out I had the altered gene.  I do not feel able emotionally to deal with testing.  Family members do not want me to get testing.	
(2) (3) (4) (5) (6) (7) (8)	I do not see any reason for learning if I have the altered gene.  It would be too upsetting to learn that I have the altered gene.  I am too worried about women in my family.  I believe I already know whether I have the altered gene.  There would not be much I could do if I found out I had the altered gene.  I do not feel able emotionally to deal with testing.  Family members do not want me to get testing.  Risk to my insurance coverage.	

Not At All Distressed	, 31		Very Distressed		
1	2	3	4	5	

Overall, how important are the opinions of the following family members in your decision whether to 12. be tested for an alteration in a breast cancer susceptibility gene?

		Not At All	A Little	Some- what	A Great Deal	Not Applic- able
a.	Sister(s)'s opinion matters	1	2	3	4	9
b.	Wife's opinion matters	1	2	3	4	9
c.	Mother's opinion matters	1	2	3	4	9
d.	Daughter's opinion matters	1	2	3	4	9
e.	Other family member(s)'s opinions matter	1	2	3	4	9

B78a.

B78b.

B78c.

B78d.

B78e.

How pressured do you feel from the following family members to get tested for the altered gene? 13. (Circle Not Applicable if you do not have any relatives in that category.)

		Not At All	A Little	Some- what	A Great Deal	Not Applic- able
a.	Sister(s)	1	2	3	4	9
b.	Wife	1	2	3	4	9
c.	Mother	1	2	3	4	9
d.	Daughter	1	2	3	4	9
e.	Other family member(s)	1	2	3	4	9

B79a.

B79b.

B79c.

B79d.

B79e.

How much of a burden is it on you when the women in your family pressure you to 14. get tested for the altered gene?

B80.

N o	A Little	Some	A Great	Not applicable,
Burden	Burden	Burden	Burden	No Pressure
1	2	3	4	5

How distressed would you be if you took the test and found that you did not have the 15. altered gene which conveys increased risk of breast cancer?

B70a.

Not At All Distressed				Very Distressed		
1	2	3	4	5		

16. If you were to take the test and find out that you <u>did not have</u> the altered gene which conveys increased risk for breast cancer, what would you expect your reactions to be?

		Strong Disagre				rongly Agree	
a.	I would feel wonderful.	1	2	3	4	5	B81a.
b.	I would feel I had been told what I knew all along.	1	2	3	4	5	В81ь.
c.	I would feel relieved.	1	2	3	4	5	B81c.
d.	I would not believe the results.	1	2	3	4	5	B81d.
e.	I would fall apart emotionally.	1	2	3	4	5	B81e.
f.	I would feel guilty.	1	2	3	4	5	B81f.
g.	I would still feel anxious.	1	2	3	4	5	B81g.
h.	I would feel angry.	1	2	3	4	5	B81h.
i.	I would feel prepared for the future.	1	2	3	4	5	B81i.
j.	I would feel I had done all I needed to do.	1	2	3	4	5	B81j.
k.	I would not feel very differently.	1	2	3	4	5	B81k.

17. How distressed would you be if you took the test and found that you **did have** the altered gene which conveys increased risk for breast cancer?

Not At All Distressed				Very Distressed
1	2	3	4	5

18. If you were to take the test and find out that you <u>had</u> the altered gene, what would you expect your reactions to be?

			Strongly Disagree			Strongly Agree		
a.	I would feel relieved about being more certain.	1	2	3	4	5		
b.	I would feel I had been told what I knew all along.	1	2	3	4	5		
c.	I would not believe the results.	1	2	3	4	5		
d.	I would feel guilty.	1	2	3	4	5		
e.	I would be depressed.	1	2	3	4	5		
f.	I would feel worried about the future.	1	2	3	4	5		
g.	I would just fall apart emotionally.	1	2	3	4	5		

B82a.

В82ь.

B69a.

B82c.

B82d.

B82e.

B82f.

B82g.

		Strong Disagr	gly eee		St	rongly Agree
h.	I would feel anxious.	1	2	3	4	5
i.	I would feel angry.	1	2	3	4	5
j.	I would not feel very differently.	1	2	3	4	5

B82h.

B82i.

B82j.

		Not A	t All		All Th	e Time
19.	How often do you worry about having the altered gene associated with risk for breast cancer among women?	1	2	3	4	5
20.	To what extent do any worries you have about this genetic alteration interfere with every day life?	1	2	3	4	5
21.	How often do you worry about women in your family developing breast cancer?	1	2	3	4	5
22.	How often do you worry about developing cancer yourself?	1	2	3	4	5
23.	How much do worries about developing cancer interfere with your everyday life?	1	2	3	4	5

B83.

B84.

B85.

B86.

B87.

How likely do you think it is that you have the altered gene which conveys increased risk for breast cancer in women relatives? (Please circle one)

B88.

0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
0	1	2	3	4	5	6	7	8	9	10

25. How much would it affect your health in the future if you had the altered gene which conveys increased risk for breast cancer in women relatives?

B89.

 $\square$  Not at All

☐ A Little

 $\square$  Somewhat

☐ A Great Deal

☐ I Don't Know (5)

Overall, what do you think your risk is of developing cancer in the future?

B90.

0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
0	1	2	3	4	5	6	7	8	9	10

#### **SYMPTOMS OF STRAIN SECTION**

Listed Below Are Some Symptoms Of Strain That People Sometimes Have. Please Read Each One Carefully And Check The Answer Which Best Reflects How Much That Symptom Has Bothered You During the Past Three Months.

		Not at all	<u>A little</u>	Quite a bit	<u>Extremely</u>	
1.	Suddenly scared for no reason	1	2	3	4	K1.
2.	Feeling fearful	1	2	3	4	K2.
3.	Faintness, dizziness, or weakness	1	2	3	4	К3.
4.	Nervousness or shakiness inside	1	2	3	4	K4.
5.	Heart pounding or racing	1	2	3	4	K5.
6.	Trembling	1	2	3	4	K6.
7.	Feeling tense or keyed up	1	2	3	4	K7.
8.	Headaches	1	2	3	4	K8.
9.	Spells of terror or panic	1	2	3	4	К9.
10.	Feeling restless, can't sit still	1	2	3	4	K10.
11.	Feeling low in energyslowed down	1	2	3	4	K11.
12.	Blaming yourself for things	1	2	3	4	K12.
13.	Crying easily	1	2	3	4	K13.
14.	Loss of sexual interest or pleasure	1	2	3	4	K14.
15.	Poor appetite	1	2	3	4	K15.
16.	Difficulty falling asleep, staying asleep	1	2	3	4	K16.
17.	Feeling hopeless about the future	1	2	3	4	K17.
18.	Feeling blue	1	2	3	4	K18.
19.	Feeling lonely	1	2	3	4	K19.
20.	Feeling trapped or caught	1	2	3	4	K20.
21.	Worrying too much about things	1	2	3	4	K21.
22.	Feeling no interest in things	1	2	3	4	K22.
23.	Thoughts of ending your life	1	2	3	4	K23.
24.	Feeling everything is an effort	1	2	3	4	K24.
25.	Feelings of worthlessness	1	2	3	4	K25.

## **FAMILY RELATIONSHIPS SECTION**

1.	Is there anyone in your life with whom you can sha holding back?	ire your m	ost priv	ate feel	ings wi	thout	C21.
	(1) $\square$ Yes (5) $\square$ No						
1	a. Do you have that kind of relationship with	your siste	e <b>r</b> (who	gave u	s your r	name)?	C21c.
2.	How often do you talk to your sister? (check one	e)					C22.
	(1) Most every day (5)	Less	than onc	e a mor	nth		
	(2) A few times a week (6)	Less	than onc	e a year	r		
	(3) A few times a month (7)	Neve	r				
	(4)Once a month						
3.	Please indicate the extent to which each of the follo	Strong Disage	gly	ntly des	Si	rongly Agree	
3a.	Planning family activities is difficult because we misunderstand each other.	1	2	3	4	5	M1.
3b.	In times of crisis we can turn to each other for support.	1	2	3	4	5	M2.
3c.	We cannot talk to each other about the sadness we feel.	1	2	3	4	5	М3.
3d.	Individuals are accepted for who they are.	1	2	3	4	5	M4.
3e.	We avoid discussing our fears and concerns.	1	2	3	4	5	M5.
3f.	We can express feelings to each other.	1	2	3	4	5	М6.
3g.	There are lots of bad feelings in the family.	1	2	3	4	5	M7.
3h.	We feel accepted for who we are.	1	2	3	4	5	M8.
3i.	Making decisions is a problem for our family.	1	2	3	4	5	М9.
3j.	We are able to make decisions about how to solve problems.	1	2	3	4	5	M10.
3k.	We don't get along well together.	1	2	3	4	5	M11.
31.	We confide in each other.	1	2	3	4	5	M12.

## **BACKGROUND DATA SECTION**

Now, we'd like to know more about you.

1.	Date of Birth	Month	Day	Year		<b>A1</b>
2.	Ethnic Background:	White Hispanic Native American	□ 1 □ 2 □ 3	Black Asian Other	☐ 4 ☐ 5 ☐ 6	A2.
3.	Religion:	Catholic Jewish Muslim	□ 1 □ 2 □ 3	Protestant Buddhist Other None	<ul><li>□ 4</li><li>□ 5</li><li>□ 6</li><li>□ 7</li></ul>	A3.
	3a. How often do	you attend religious se	rvices?			A3a.
	☐ 1 Less Tha	n Once a Month	□ 5 A F	ew Times A M	Ionth or More	
	3b. How important	are religious and spiri	tual beliefs	in your life?		A3b.
	Not at All			Very Imp	oortant	
	1	2 3	4	5		
4.	Are you currently (pl	ease check one)?		ied married, but liv iage-like relatio rated rced	ing in a steady, nship	A4.
5.	If you are currently ma	arried, what was the da	ate of your o	current marriage	e?	A5.
	Month	Year				
	5a. Is this your firs	t marriage? (1) ☐ Ye	s (5)	No		A5a.
6.	How many children do	you have?				A6.
	6a. Number of childr	ren living at home? _				A6a.
	6b. Number who are	under age 6?				A6b.
	6c. Number of Daug	hters? _				A6c.
7.	Do you plan to have me	ore children? (1	ı) 🗆 Yes	(5) No	(3) Undecided	A12.
	7a. If yes, how ma	ny more children? _				A12a

8.	In general, would y	ou say your healt	h is:			I1.
	☐ Excellent (1)	□ Very Good	☐ <b>G</b> ood (3)		□ Fair 4)	☐ Poor (5)
9.	Are you currently v	working for pay ou	itside the home?			A7.
10.	If <u>yes</u> , about how r	nany hours per we	eek are you workin	ng for pay	?	A8.
	Less than 10 (1)	10-20 (2)	21-30	31-40 (4)	41 or more (5)	
11.	What is the highest 1  1   Less than 9th 2   Dropped out 3   Completed hi 4   Some college	grade of high school gh school	you have complete 5 □ 6 □ 7 □	Complete Some gra	ed college duate or professi	A9. ional training ofessional training
The	following two quest	ions are optiona	l, but we hope the	at you will	l provide this in	formation.
12.	What is your househ	old's total income	e? (Check one)			A10.
	(1) ☐ Less than \$ (2) ☐ \$10,000 to (3) ☐ \$20,000 to	\$19,999 (5)	□ \$30,000 to \$3 □ \$40,000 to \$4 □ \$50,000 to \$5	9,999		to \$69,999 r than \$69,999
13.	How many people	(adults and childre	en) does this incom	e support?		A11.

## THANK YOU VERY MUCH FOR YOUR PARTICIPATION.

				1
1 1	l i			۱
1 1	! !	l i	1 1	l
1 1		1 1	1 1	 l





# WOMEN'S HEALTH STUDY

Post-Results Questionnaire

TODAY'S DATE	
IODAISDAID	

ID	

#### POST-RESULTS ASSESSMENT

## **Genetic Testing Section**

1	When die	l vou receiv	e your results	s of	genetic	testing?
1.	w nen die	i vou leceiv	e your resum	3 O.	gonouv	woung.

B101.

(Month/Year)	
--------------	--

- 2. What were the results of testing?
  - 1 ☐ Positive for BRCA1/BRCA2
  - 2 
    Negative for BRCA1/BRCA2, but at least one family member was found to be Positve
  - 3 ☐ Negative for BRCA1/BRCA2 and all Family members who were tested were negative for BRCA1/BRCA2
- 2. Did you do any of the following <u>before</u> obtaining your results?

	•			
		Yes	<u>N o</u>	
a.	Prophylactic Mastectomy	1	5	B102a.
b.	Prophylactic Oophorectemy	1	5	В102ь.
c.	Regular Breast Self-Exams (Monthly)	1	5	В102с.
d.	Regular Physical Exams	1	5	B102d.
e.	Regular Mammograms	1	5	B102e.
f.	Encourage your relatives to be tested	1	5	B102f.
g.	Discourage your relatives from being tested	1	5	B102g.
				4

3. Please rate the extent to which <u>each of</u> the following were your reasons for getting your results.

		Not at All				Very Much So	
a.	To plan for the future.	1	2	3	4	5	B16b1.
b.	To reduce the uncertainty.	1	2	3	4	5	B16b2.
c.	To know I have to be more careful about doing breast self examinations and getting regular checkups.	1	2	3	4	5	B16b3.
d.	To make decisions about whether to get prophylactic surgery.	1	2	3	4	5	B16b4.
e.	To make decisions about family planning.	1	2	3	4	5	B16b5.
f.	To find out the risk that may be transmitted to my children.	1	2	3	4	5	B16b6.
g.	Family members wanted me to get testing.	1	2	3	4	5	B16b7.
h.	Other (describe)	1	2	3	4	5	B16b8.

4. Before getting your test results, how distressing had it been for you to know that your family may be at increased risk for breast cancer because of your family history?

Not At All Distressing				Very Distressing
1	2	3	4	5

B66b.

5. How distressed **did you expect to be** when you were told you have an altered BRCA1/BRCA2 gene (before you received results)?

Not At All Distressed				Very Distressed
1	2	3	4	5

B68b.

6. How distressed were you when you were told that you had an altered BRCA1 (or BRCA2) gene?

Not At All Distressed				Very Distressed
1	2	3	4	5

B69b.

7. Overall, do you regret the decision to obtain your results?

Not At All				Very Much So
1	2	3	4	5

B71a.

8. When you received your results, what were your immediate reactions?

		Not At All			1	Very Much So	
a.	I felt relieved about being more certain.	1	2	3	4	5	B82a.
b.	I felt I had been told what I knew all along.	1	2	3	4	5	В82ь.
c.	I did not believe the results.	1	2	3	4	5	В82с.
d.	I felt guilty.	1	2	3	4	5	B82d.
e.	I was depressed.	1 .	2	3	4	5	B82e.
f.	I worried about the future.	1	2	3	4	5	B82f.
g.	I thought I would just fall apart emotionally.	1	2	3	4	5	B82g.
h.	I felt anxious.	1 .	2	3	4	5	B82h.
i.	I felt angry.	1	2	3	4	5	B82i.

9. We are interested in the decisions women make after being notified of the results of their testing. <u>After</u> obtaining your results, which options are you now considering? Please circle one response.

		Definitely Will NOT Do	Probably Will NOT Do	Probably Will <u>Do</u>	Definitely Will <u>Do</u>	Done After Obtaining <u>Results</u>	Does <u>Not</u> <u>Apply</u> to Me	
a.	Prophylactic Oophorectomy	1	2 .	3	4	5	-8	B103a.
b.	Prophylactic Mastectomy	1	2	3	4	5	-8	B103b.
c.	Regular Breast Self-Exams (Monthly)	1	2	3	4	5	-8	В103с.
d.	Regular Physical Exams	1	2 .	3	4	5	-8	B103d.
e.	Regular Mammograms	1	2	3	4	5	-8	B103e.
f.	Encouraging my relatives to be tested	1	2	3	4	5	-8	B103f.
g.	Discouraging my relatives from being tested	1	2 .	3	4	5	-8	B103g.
h.	Telling some of my relatives what my results were	1	2	3	4	5	-8	B103h.
i.	Not telling some of my relatives what my results were	1	2	3	4	5	-8	B103i.

10. For each of the following areas of your life, please indicate how much these decisions/plans have been affected by the results of genetic testing?

B35c.

B36c.

B37c.

B38c.

		Not at all Affected				ery Much Not Affected Applicable		
a.	Decisions about having children	1	·2	3	4	5	-8	
b.	Decisions about forms of birth control	1	2	3	4	5	-8	
c.	Decisions about which steps to take to prevent breast cancer	1	2	3	4	5	-8	
d.	Decisions about work and career	1	.2	3	4	5	-8	

		Not at a				ry Much ffected	Not Applicable	
e.	Decisions about savings and financial planning	1	2	3	4	5	-8	В:
f.	Plans for your future	1	·2	3	4	5	-8	В
g.	Plans for your daughter's future	1	2	3	4	5	-8	В4

39c.

40c.

42c.

Do you feel you have enough information about breast cancer to make any decisions that might be 11. necessary?

Not At All						Very Much
1	2	3	4	5	6	7

B43.

Do you feel you have enough information about ovarian cancer to make any decisions that might be 12. necessary?

Not At All			•			Very Much
1	2	3	4	5	6	7

B43a.

Do you feel you were adequately informed about the benefits and drawbacks of genetic 13. testing for risk of breast and ovarian cancer before getting your results?

Not At All			,			Very Much
1	2	3	4	5	6	7

B44a.

Do you now feel you are adequately informed about what you can do to reduce 14. your risk of breast cancer since you have an altered BRCA1/BRCA2 gene?

Not At All						Very Much	B45a
1	2	3	4	5	6	7	

5a.

B45b.

Do you now feel you are adequately informed about what you can do to reduce 15. your risk of ovarian cancer since you have an altered BRCA1/BRCA2 gene?

Not At All			•		Very Much	
1	2	3	4	5	6	7

Do you now feel you are adequately informed about the benefits and drawbacks of each option 16. available to women who have an altered BRCA1/BRCA2 gene?

Not At All			,			Very Much
1	2	3	4	5	6	7

B46a.

Do you feel you are adequately informed about what it will mean for your children 17. that you have an altered BRCA1/BRCA2 gene?

Not At All			•			Very Not Much Applicable		B47
1	2	3	4	5	6	7	-8	

7a.

How confident are you that you will cope effectively with the finding that you have an altered 18. BRCA1/BRCA2 gene?

Not At All								
1	2	3	4	5	6	7		

B48e.

How confident are you that your family members will cope effectively with the finding that you have 19. an altered BRCA1/BRCA2 gene?

Not At All							
1	2	3	4	5	6	7	

R48f.

## **Personal Attitudes Section**

Now, we would like to ask you some questions about your concerns of breast cancer? 1.

		Not At All				All The Time	
a.	How often do you worry about developing breast cancer or developing breast cancer again?	1	2	3	4	5	B27.
b.	To what extent do these worries interfere with your every day life?	ĺ	2	3	4	5	B28.
c.	How often do you worry about developing ovarian cancer or developing ovarian cancer again?	1	2	3	4	5	B110.

		Not.At All				All The Time	
d.	To what extent do these worries interfere with your every day life?	1	2	3	4	5	B111.
e.	How often do you worry about having an altered gene associated with risk for breast or ovarian cancer?	1	2	3	4	5	B29.
f.	To what extent do worries about having an altered gene interfere with your everyday life?	1	2	3	4	5	В30.
g.	How often do you worry about your relatives developing breast or ovarian cancer?	1	2	3	4	5	B106.
h.	To what extent do these worries interfere with your every day life?	1	2	3	4	5	B107.
i.	How often do you worry about your relatives having an altered gene associated with risk for breast and ovarian cancer?	1	2	3	4	5	B108.
j.	To what extent do these worries interfere with your every day life?	1	2	3	4	5	B109.

# Health, Mood, and Activities

1.	In general, wo	uld you say your healt	h 18:					
	☐ Excellent	☐ Very Good	☐ Good	☐ Fair	☐ Poor			
2.	Compared to one year ago, how would you rate your health in general now?(Check one)							
		Much better now than	one year ago					
		Somewhat better now	than one year ago					
		About the same as on	-					
		Somewhat worse nov	v than one year ago	)				
		Much worse than one	year ago					

3. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much? *Please mark the appropriate box to indicate your response.* 

		YES, limited a lot.	YES, limited a little.	NO, not limited at all.
a.	Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports.	1	2	3
b.	Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.	1 .	2	3
c.	Lifting or carrying groceries.	1	2	3
d.	Climbing several flights of stairs.	1	2	3
e.	Climbing one flight of stairs.	1 .	2	3
f.	Bending, kneeling, or stooping.	1	2	3
g.	Walking more than a mile.	1	2	3
h.	Walking several blocks.	1	2	3
i.	Walking one block.	1 ,	2	3
j.	Bathing or dressing yourself.	1	2	3

Durin other	the past 4 weeks, have you had any of the following problems with your work or gular daily activities as a result of your physical health?
4a.	Cut down the amount of time you spent on work or other activities.  (1)  Yes  (5)  No
4b.	Accomplished less than you would like.  (1) □ Yes (5) □ No
4c.	Were limited in the kind of work or other activities.  (1) $\square$ Yes (5) $\square$ No
4d.	Had difficulty performing the work or other activities (for example, it took extra effort).  (1) $\square$ Yes (5) $\square$ No

4.

5.	other	<b>During the past 4 weeks</b> , have you had any of the following problems with your work or other regular daily activities as a result of any <b>emotional</b> problems (such as feeling depressed or anxious)?									
	5a.	Cut down the ar	mount of timer activities.	e you spent	(1) 🗆 <b>Y</b>	(1) ☐ Yes (5) ☐ No					
	5b.	Accomplished 1	less than you	would like.	(1) 🗆 <b>Y</b>	es (5) □	□ No				
	5c.	Didn't do work carefully as usu		vities as	(1) 🗆 <b>Y</b>	es (5) [	□ <b>N</b> o				
6.	<b>Duri</b> proble group	ng the past 4 we ems interfered win	eks, to what th your norm	extent has just act	your physica ivities with f	al health or o amily, friend	emotional ds, neighbors	s, or			
	• •	(1) □ Not at all	(2)  ☐ Slightly	(3) □ M	oderately	(4) □ <b>Q</b> uite a	(5)	Extremely			
7.	. How much bodily pain have you had during the past 4 weeks?										
		(1) □ Not at all	(2) □ Slightly	(3) □ M	loderately	(4)  Quite a	a bit $\Box$	Extremely			
8.	<b>Duri</b> work	ng the past 4 we outside the home	eks, how my and housew	uch did pain ork)?	interfere wi	ith your nor	mal work (ir	ncluding bot	h		
		(1) □ Not at all	(2) □ Slightly	(3) □ M	loderately	(4)  Quite a	(5)	Extremely			
9. For the	each que	e questions are abstion, please give ing the past 4 we	the one ansy	ver that com	es closest to	the way you	have been t	eeling. How	eeks.  much of		
			All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time			
a.	Did you	feel full of pep?	1	2	3	4	5	6			
b.	Have yo nervous	u been a very person?	1	2	3	4	5	6			

c.	Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
d.	Have you felt calm and peaceful?	1	2	3	4	5	6

		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
e.	Did you have a lot of energy?	1	2	3	4	5	6
f.	Have you felt downhearted and blue?	1	2	3	4	5	6
g.	Have you been a happy person?	1	2	. 3	4	5	6
h.	Did you feel tired?	1	2	3	4	5	6

# **Mood Section**

1.	During	g the past 4 weeks, hered with your social ac	ow much of the	e time has	your physic	cal health or en	notional problem	ms
	☐ All the t	of	☐ A good bit the time		Some of the time	☐ A little of the time	☐ None of the time	
2.	blue, o	past 6 months, have or depressed or in whice liked to do for fun?	you had two we h you lost all in	iterest in th	ings like w	ork or hobbies (	you felt sad, or things you	I12.
	2a.	If there was such a tyrelationships suffer?  (1) □ Yes		d in <b>the pa</b>	st 6 month	ns, did your wo	ork or	I12a.
	2b.	If there was such a two counseling or psychology (1) ☐ Yes	therapy?	d in <b>the pa</b>	st 6 month	ns, did you get		I12b.
	2c.	If there was such a ty medication for this co (1) □ Yes	ndition?	d in <b>the p</b> a	st 6 montl	ns, did you get		I12c.
3.	Have y or depi	you <b>ever in your lifet</b> ressed <u>or</u> in which you fun?	lost all interest	in things l	ike work or	hobbies or thir	igs you usually	lue, liked to I14
			$(1) \square Yes$	(5) □ No	(Skip to Q	uestion 4, next	page)	
	3a.	If there was such a tr $(1) \square Yes$	wo-week period (5)  No	d, did your	work or rel	ationships suffe	er?	I14a.
	3b.	If there was such a tw (1) $\square$ Yes	vo-week period, (5)  No	, did you go	et counselir	ng or psychothe	rapy?	I14b.
	3c.	If there was such a tw (1) $\square$ Yes	wo-week period (5)  No	l, did you g	et medicati	on for this cond	lition?	I14c.

4. Are you **currently** receiving counseling, psychotherapy or medication for depression or emotional problems?

I13.

(1) □ Yes

(5) 🗆 No

### **Coping Section**

1. Sometimes people can find unexpected benefits in difficulties. We are interested in the ways in which you might have made positive use of your knowing that you have an altered gene which increases the risk of breast cancer. For each of the statements below, indicate the degree to which your life has been affected positively by your finding you have an altered gene.

		Not At All	A Very Small Degree	A Small Degree	A Moderate Degree	A Great Degree	A Very Great Degree	
a.	My priorities about what is important in life.	1	2	3	4	5	6	L6a.
b.	I'm more likely to try to change things which need changing.	1	2	3	4	5	6	L6b.
c.	An appreciation for the value of my own life.	1	2	3	4	5	6	L6c.
d.	A feeling of self-reliance.	1	2	3	4	5	6	L6d.
e.	A better understanding of spiritual matters.	1	2	3	4	5	6	L6e.
f.	Knowing that I can count on people in times of troubles.	1	2	3	4	5	6	L6f.
g.	A sense of closeness with others.	1	2	3	4	5	6	L6g.
h.	Knowing I can handle difficulties.	1	2	3	4	5	6	L6h.
i.	A willingness to express my emotions.	1	2	3	4	5	6	L6i.
j.	Being able to accept the way things work out.	1 .	2	3	4	5	6	L6j.
k.	Appreciating each day.	1	2	3	4	5	6	L6k.
1.	Having compassion for others.	1	2	3	4	5	6	L61.
m.	I'm able to do better things with my life.	1	2	3	4	5	6	L6m.
n.	New opportunities are available which wouldn't have been otherwise.	1	2	3	4	5	6	L6n.

2. This set of questions deals with ways you've been coping with the stress in your life that goes with knowing you have an altered gene associated with increased risk for breast cancer. Obviously, different people deal with things in different ways, but we are interested in how you've tried to deal with it. Each item says something about a particular way of coping. We 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 it seems to be working, but just whether or not you're doing it. Use these response choices below and try not to let one answer influence another. Make your answers as true FOR YOU as you can.

		I haven't been doing this at all	I've been doing this a little bit	I've been doing this some	I've been doing this a lot	
a.	I've been turning to work or other activities to take my mind off things.	· 1	2	3	4	L7a.
b.	I've been concentrating my efforts on doing something about my situation.	1	2	3	4	L7b.
c.	I've been saying to myself "this isn't possible."	1	2	3	4	L7c.
d.	I've been using alcohol or other drugs to make myself feel better.	' 1	2	3	4	L7d.
e.	I've been getting emotional support from others.	1	2	3	4	L7e.
f.	I've been giving up trying to deal with it.	1	2	3	4	L7f.
g.	I've been taking action to try to make the situation better.	1	2	3	4	L7g.
h.	I've been refusing to believe that it is possible that I have an altered gene.	1	2	3	4	L7h.
i.	I've been saying things to let my unpleasant feelings escape.	1	2	3	4	L7i.
j.	I've been using alcohol or other drugs to help me get through it.	1	2	3	4	L7j.
k.	I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4	L7k.
1.	I've been trying to come up with a strategy about what to do.	1	2	3	4	L71.
m.	The standard and an denote and in a	1	2	3	4	L7m.

		I haven't been doing this at all	I've been doing this a little bit		I've been doing this a lot	
n.	I've been giving up the attempt to cope.	1	2	3	4	L7n.
0.	I've been accepting the possibility that I might have an altered gene.	1	2	3	4	L70.
p.	I've been expressing my negative feelings.	1	2	3	4	L7p.
q.	I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4	L7q.
r.	I've been learning to live with the possibility that I have an altered gene.	1	2	3	4	L7r.
s.	I've been thinking hard about what steps to take.	. 1	2	3	4	L7s.
t.	I've been praying or meditating.	1	2	3	4	L7t.
u.	I've been making fun of the situation.	1	2	3	4	L7u.

The following items are to be answered only by those women who are married or living with a partner.

 $\square$  If not married or living with a partner skip to the Mood section, next page.

		I haven't been doing this at all		I've been doing this some		
v.	I've been denying or hiding my anger around my spouse/partner.	. 1	2	3	4	Lv.
w.	I've been denying or hiding my worries around my spouse/partner.	1	2	3	4	Lw.
x.	I've been avoiding talking about my problems around my spouse/partner.	1	2	3	4	Lx.
y.	I've acted more positive around my spouse/partner than I feel.	1	2	3	4	Ly.

## **Symptoms of Strain Section**

LISTED BELOW ARE SOME SYMPTOMS OF STRAIN THAT PEOPLE SOMETIMES HAVE. Please Read Each One Carefully And Check The Answer Which Best Reflects How Much That Symptom Has Bothered You During the <u>Past Three Months</u>.

		Not at all	<u>A little</u>	<u>Quite a bit</u>	<u>Extremely</u>	<b> </b> -
1.	Suddenly scared for no reason	1 ·	2	3	4	K1.
2.	Feeling fearful	1	2	3	4	K2.
3.	Faintness, dizziness, or weakness	1	2	3	4	K3.
4.	Nervousness or shakiness inside	1	2	3	4	K4.
5.	Heart pounding or racing	1	2	3	4	K5.
6.	Trembling	1 .	2	3	4	K6.
7.	Feeling tense or keyed up	1	2	3	4	K7.
8.	Headaches	1	2	3	4	K8.
9.	Spells of terror or panic	1	2	3	4	K9.
10.	Feeling restless, can't sit still	1	2	3	4	K10.
11.	Feeling low in energyslowed down	1	2	3	4	K11.
12.	Blaming yourself for things	1	2	3	4	K12.
13.	Crying easily	1	2	3	4	K13.
14.	Loss of sexual interest or pleasure	1	2	3	4	K14.
15.	Poor appetite	1	2	3	4	K15.
16.	Difficulty falling asleep, staying asleep	1	2	- 3	4	K16.
17.	Feeling hopeless about the future	1	2	3	4	K17.
18.	Feeling blue	1	2	3	4	K18.
19.	Feeling lonely	1	2	3	4	K19.
20.	Feeling trapped or caught	1	2	3	4	K20.
21.	Worrying too much about things	1	2	3	4	K21.
22.	Feeling no interest in things	1	2	3	4	K22.
23.	Thoughts of ending your life	1	2	3	4	K23.
24.	Feeling everything is an effort	1	2	3	4	K24.
25.	Feelings of worthlessness	1 .	2	3	4	K25.

### **Relationships Section**

- Is there anyone in your life with whom you can share your most private feelings without holding back?
   (1) □ Yes
   (5) □ No

  C21.
- 2. Next, we are interested in any changes that getting the results of testing has had on your close relationships. How has your knowing your test results affected your relationship with the following relatives?

		Much less close	A Little Less Close	No Change	A Little More Close	Much More Close	No Living Relatives in this Category
a.	Spouse/Partner	1	2	. 3	4	5	-8
b.	Children	1	2	3	4	5	-8
c.	Parent(s)	1	2	3	4	5	-8
d.	Sister(s)	1	2	3	4	5	-8

- 3. Have any of your female relatives received their test results?
  - (1)  $\square$  Yes (5)  $\square$  No
- 4. Have any been told they have an altered gene for risk of breast cancer?
  - (1)  $\square$  Yes (5)  $\square$  No
- 5. Overall, has your relationship to them changed?

Much less close	A Little Less Close	No Change	A Little More Close	Much More Close
1	2	3	4	5

- 6. Have any been told they **do not have** an altered gene for risk of breast cancer?
  - (1)  $\square$  Yes (5)  $\square$  No
- 7. Overall, has your relationship to them changed?

Much less close	A Little Less Close	No Change	A Little More Close	Much More Close
1	2	3	4	5

Thank You Very Much For Your Participation!