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AWARD NUMBER DAMD17-96-1-6157

TITLE: Stress and Coping in Genetic Testing for Cancer Risk

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REPORT DATE: July 1998

TYPE OF REPORT: Annual

PREPARED FOR: Commander
U.S. Army Medical Research and Materiel Command
Fort Detrick, Maryland 21702-5012

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REPORT DOCUMENTATION PAGE

Form Approved
OMB No. 0704-0188

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1. AGENCY USE ONLY <i>(Leave blank)</i>	2. REPORT DATE July 1998	3. REPORT TYPE AND DATES COVERED Annual (15 Jun 97 - 14 Jun 98)	
4. TITLE AND SUBTITLE Stress and Coping in Genetic Testing for Cancer Risk		5. FUNDING NUMBERS DAMD17-96-1-6157	
6. AUTHOR(S) James C. Coyne, Ph.D.			
7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES) University of Michigan Ann Arbor, Michigan 48109-0708		8. PERFORMING ORGANIZATION REPORT NUMBER	
9. SPONSORING / MONITORING AGENCY NAME(S) AND ADDRESS(ES) U.S. Army Medical Research and Materiel Command Fort Detrick, Maryland 21702-5012		10. SPONSORING / MONITORING AGENCY REPORT NUMBER	
11. SUPPLEMENTARY NOTES			
12a. DISTRIBUTION / AVAILABILITY STATEMENT Approved for Public Release; Distribution Unlimited		12b. DISTRIBUTION CODE <div style="font-size: 2em; text-align: center;">19981210 088</div>	
13. ABSTRACT <i>(Maximum 200 words)</i> <p>Predictive testing is now possible for altered genes which convey heightened risk of breast and ovarian cancer. Testing is already being offered to our sample of high-risk women who have been participating in genetic linkage and mutation studies and it is becoming more generally available. In the absence of prior research, we are faced with a 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 project involves a prospective study of high risk women drawn from a hereditary cancer registry 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. The second year of the project was marked by the continued progress of the study, including movement of some women into the follow up phase. Important results include findings concerning the nature of social support processes in these high risk families and the gathering of further evidence of the positive adjustment of these women. Comparative studies utilizing community samples are also being launched.</p>			
14. SUBJECT TERMS Breast Cancer		15. NUMBER OF PAGES 320	
		16. PRICE CODE	
17. SECURITY CLASSIFICATION OF REPORT Unclassified	18. SECURITY CLASSIFICATION OF THIS PAGE Unclassified	19. SECURITY CLASSIFICATION OF ABSTRACT Unclassified	20. LIMITATION OF ABSTRACT Unlimited

FOREWORD

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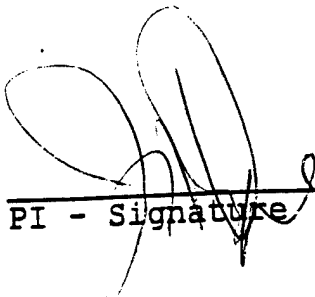
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INTRODUCTION

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. Only about 5-10% of all breast cancer is believed to be hereditary in nature, but this figure could be as high as 20% for early onset breast cancer. Furthermore, it has been estimated that 15-45% of all families with multiple cases of breast cancer and as much as 80% of families with elevated rates of both early-onset breast and ovarian cancer carry mutations of either BRCA1 or BRCA2, although these figures may be somewhat lower in the general population than in the hereditary breast and ovarian cancer registries from which they were derived. It has also been estimated that female carriers have a 55-85% risk of developing breast cancer and a 20-40% risk of developing ovarian cancer before the age of 70. Male carriers of these altered genes are at somewhat increased risk for prostate and colon cancer, and male carriers of BRCA2 have a 6% risk of breast cancer. Cancer susceptibility conferred by BRCA1 and BRCA2 mutations is transmitted as an autosomal dominant trait which means that the mutations are inherited from either parent, and offspring have a 50% risk of inheriting the parental mutation. Options for women who test positive for an altered gene related to breast cancer include increased surveillance, prophylactic mastectomy and Oophorectomy, and for some, participation in a chemo-prevention trial. None of these measures have proven to be entirely efficacious and all have known limitations.

Testing has been 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 available in the community. As many as 1 in 300 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 genetic 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 intend to obtain testing actually follow through with it. Furthermore, little is known about the anticipated benefits and drawbacks of knowledge of risk status which influence 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 were faced with an urgent need for basic descriptive data concerning women at high-risk for early onset breast cancer and their families, including their psychosocial assets and liabilities, their attitudes and beliefs, their intention to seek predictive testing, and their preparedness for possible results. This information was needed immediately for in planning for testing becoming made available on such a large scale basis. Yet, we also recognized that we had a historical opportunity to utilize these data in a prospective study of stress, coping, and decision making processes in these women and their families. We had the advantage of initial data having been obtained just prior to predictive testing for BRCA1 and BRCA2 becoming an option for the individual women.

The project was designed as 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 BRCA2 and their family members. With expansion of the Hereditary Breast and Ovarian Cancer registry we have been increasing our sample to almost 500 women which is now our goal. Women participating in our study receive baseline in-depth assessment by questionnaire and telephone interview. 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, within 8 weeks after receipt of any results, and 6 and 12 months after testing. Husbands of the high risk women are also assessed by questionnaire and they are being reassessed along with siblings of the women at 6 months following the women's receipt of results. 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 has been 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 in

evaluating the incremental distress associated with receipt of results. That is, levels of distress and morbidity following disclosure need to be evaluated in terms of what these levels were prior to disclosure. Without these data, it could not be determined if psychological distress and disorder following testing actually represent a reduction from pre-existing levels. The second objective has been 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 has been 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. Thus, 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.

In the second year, we have also had the objective of addressing the issue of social support processes in the lives of high risk women. This objective will continue as the women progress through the opportunity to obtain results and the follow up periods. However, it was important to establish the role of social support in their initial adjustment. Furthermore, we were interested in the involvement of husbands in the women's decision making concerning cancer risk management and whether to get testing. Spouses are usually the most important source of support for married persons (Brown & Harris, 1978; Coyne & DeLongis, 1986). Yet, the women in our study are members of high risk families, with first-degree female relatives in similar predicaments. The support and information close female relatives provide, how these relatives cope with their own dilemma, and the decisions about testing they make are likely to have profound effects on the high risk women. It may be that as a result of the mobilization of social support around the shared risk of cancer, female relatives come to have more influence on the distress levels of these women, and the spouses correspondingly less.

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 family members being affected by cancer and who will be among the first persons to have access to testing for alterations of the BRCA1 and BRCA2 genes (2) the spouses of the approximately 400 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; 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. Initial assessment of the proband women is by self-report questionnaires and telephone interviews. Subsequent reassessments of the proband women's current cancer-related stress, support and beliefs, attitudes and intentions, distress, and psychiatric morbidity will also be by telephone interview and questionnaire. The assessment of husbands and siblings is by self-report questionnaires. The at-risk women, spouses and siblings are then reassessed as the option of predictive testing is made available to the individual women. A second reassessment of the individual women will occur after 8 weeks testing has occurred and results are available, or when results would have been available had the proband woman not declined testing. Follow up assessments will occur at 6 and 12 months.

PROCEDURE AND ACCOMPLISHMENTS TO DATE

Summary

As reported in our first annual report, the initial year of the study 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 known BRCA1 or BRCA2 mutation are not generally 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. As noted below, there may also be an increased psychological burden on affected women seeking testing: Whether family members can be tested will depend on their results. 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 the opportunity to get their results 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 Long Term Follow up 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.

Our second year has been marked by sustained progress. We have continued data collection, refined our research objectives, and modified our instrumentation based on initial results. Our interim assessment continues to allow us to monitor state variables and obtain additional trait measures for women having more than a year elapse between initial assessments and actually being offered testing. We have also been responding proactively to a number of exigencies, including a lower uptake of genetic testing than anticipated and a greater proportion of noninformative results among women who obtain testing. We have been enrolling new women in the study as women get recruited to the larger Hereditary Breast and Ovarian Cancer Registry. This should continue through this next year. As anticipated, women who were already enrolled in our sample are continuing to receive the opportunity to obtain testing. Some have now progressed to 6 month follow up. Based on initial results, we are setting up data collection from samples of women in the community seeking genetic testing, and we have also been adapting instrumentation to women who receive uninformative results.

Women who had initially expressed interest in testing are responding at a lower rate than anticipated to the actual opportunity to obtain their individual results. Some of their declining of testing is passive, expressed by members of high risk families not responding to letters notifying them that their results are now available or by their

not returning consent forms. This is quite consistent with past experience with testing of persons at risk for Huntington's disease, but it remains an important phenomenon to study. Another investigator group has concluded that members of high risk families who decline testing in may suffer adverse psychological consequences (Lerman et al., 1997). However, we have shown that declining testing may represent a rational decision to defer testing when other stressors are present in women's lives (Coyne, Weber, & Sonis, in press). Furthermore, it appears that decliners remain at lower levels of distress than a comparison group of patients drawn from primary care waiting rooms. Nonetheless, we have designed and implemented systematic follow up of such decliners in order to minimize selection bias in our data. Furthermore, we will be using our initial data to explore predictors of discrepancies between initial intention to obtain testing and actually obtaining it.

There has been a higher proportion of women in our sample than anticipated who have been affected by breast or ovarian cancer, but who are not found to have a known mutation of BRCA1 or BRCA2. This is consistent with other evidence of the existence of additional genes associated with hereditary risk for cancer. However, it poses some important psychosocial issues which we are exploring. Namely, affected women who receive uninformative results could experience distress because they are left in a highly ambiguous situation with respect to their own risk and that of family members. Their prior coping efforts may have been organized in the belief that testing would resolve a profound uncertainty in their lives, namely, whether being in a high risk family meant that they were personally at increased risk of cancer. Also, many of these women will have expressly sought testing to aid family members in determining their individual risk. We are tracking these women and adapting our instrumentation to their predicament. This is likely to be a widespread issue with testing in community settings. We are in what amounts to a unique situation in investigating the effects of noninformative results. Other investigators are relying on hereditary registries in which a smaller number of large families have known mutations. As a result, they are unlikely to have as many members of high risk families receiving uninformative results.

Initial results revealed that women in our sample were socially advantaged in terms of education, income, and marital stability. This is consistent with what has occurred with genetic counseling and testing more generally, and Huntington's disease in particular. Yet, because of media attention, the prevalence of mutations of BRCA1 and BRCA2, and the promise of potentially modifying risk of cancer, interest in genetic testing may be higher in the general population than for other late onset conditions. It is therefore crucial to understand differences between registry samples and women from the general population expressing an interest in testing. Without appropriate comparisons, generalizing from samples derived from hereditary cancer registries may be unwise. We have taken two important steps to address this issue. First, we have sought use of CCOP samples in Michigan and Ohio by formally submitting a concept

letter to Dean Brenner, M.D. Upon approval, we will proceed with negotiation of data collection in these community settings. Secondly, we are in the process of negotiating data collection from clinics in the University of Pennsylvania Medical System. Availability of these comparison samples will substantially increase the utility of data we have been collecting from our registry sample.

Our initial findings have also been that women in our sample are remarkably free of psychological distress and psychiatric morbidity. Basically, we set out to study a population ostensibly at psychological risk and we are encountering one which apparently is quite resilient. To better understand these issues, we have refined our assessments of these women's appraisal of the opportunity to obtain testing. Our scaling technique for this is an important methodological innovation in itself. We also have taken advantage of our interim assessment of the women in our sample and the initial assessment of their husbands to explore the role of social support processes in the apparent resiliency of these women. One hypothesis is that explicit awareness of the high risk status of these families has led to the mobilization of support processes organized around this status. If this is so, women in the community seeking testing may not share this advantage. This should prove to be one of the many valuable points of comparison between our registry and community samples.

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. There were two sets of criteria by which women could 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 other family member who had been affected. 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 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. After 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 mail-back 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 are 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, ask them to provide names and permission to contact these relatives.

Our initial sample is now variously at the point of receiving pretesting, immediate post-testing, or 6 month follow up assessments. Our recruitment and assessment of spouses and sisters proceeded on schedule. We are also adapting our schedule of assessment for women who are newly recruited into the hereditary cancer registry.

As noted in last year's report, our ability to track these women and their families through the course of their being offered testing was dependent upon them actually being given this opportunity. A number of factors affected the offering of testing in general and to specific individuals. Actual testing is now proceeding in our sample, but only after considerable delay and is almost entirely limited to affected individuals or a few other women in families with known mutations. Accurate 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, then 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 specific 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. This 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 that not every individual is appropriate for testing. For the University of Pennsylvania Hereditary Breast and Ovarian Cancer Registry, the decision was made to analyze first already collected blood samples from affected women. If an affected woman was found to have a mutation, testing is 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 and as noted above, we have instituted follow up assessments of them.

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 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 continue to coordinate our assessments with information from the University of Pennsylvania and collect data as women proceed through the process of being given the opportunity to obtain test results.

Measures

Our selection of measures meets or exceeds what was proposed in our original grant application. Copies of our batteries of instruments are included as an appendix and this year's report contains recent additions tailored to the progression of the study. Tables 1 (next page) lists the major measures.

Table 1: Initial Data Collection

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

Husbands Questionnaire

Demographics	COPE	Stressful Life Events
Health Locus of Control	Knowledge, Beliefs and Attitudes	CBCL
Risk Perception	Anticipated Reactions	LOT, MBSS, Hopkins-25, MOS-36
Worries About Wife's Risk of Cancer	Social Support & Cancer-Related Support Processes	AUDIT
Preference for Wife's Testing		DAS, FAD
Relationship-Focused Coping		

Sample

Our sample currently consists of 480 women who have completed baseline assessments. Of these, 472 completed the telephone interviews. To date, 363 interim assessments have been collected. Data from husbands are collected at the point of the women's interim assessment, and at this time, data have been collected from 224 husbands. Pre-Results data have been collected from 57 Probands and 58 siblings (25 brothers and 33 sisters). As of this report, 19 women have had their first post-results assessment and 11 have progressed to their 6 month follow up. We expect the rate of receipt of test results to increase markedly over the next few months. In addition, follow up data have been collected from 15 men and women in the long term follow up subsample. Table 2 presents an update of 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.

Table 2

Demographic Characteristics by Breast Cancer and Marital Status.

	<u>Affected</u>		<u>Unaffected</u>	
	<u>Married</u> (N=182)	<u>Not Married</u> (N=32)	<u>Married</u> (N=212)	<u>Not Married</u> (N=47)
Age	50.09 (10.56)	60.32 (12.41)	45.27 (10.70)	49.99 (16.38)***
Percent white	98.9%	96.9%	97.6%	97.9%
Percent Christian	68.3%	83.9%	80.2%	76.6%*
Percent completed some college	81.9%	67.7%	81.6%	83.0%
Percent employed outside home	62.6%	53.3%	65.4%	61.7%
Household income	\$53,600	\$25,000	\$53,900	\$33,900*
Percent first marriage	81.7%	NA	81.3%	NA
Percent ovarian cancer diagnosis	3.4%	10.0%	NA	NA
Years since breast cancer diagnosis	7.55 (5.79)	12.54 (8.79)	NA	NA
Percent in remission	89.9%	92.6%	NA	NA

* $p < .05$, ** $p < .01$, *** $p < .001$

Interest in Obtaining Testing

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. Given the low rate of uptake of testing, an objective for our third year will be to model the discrepancy between intention and actually receiving test results using our full battery of psychosocial predictors.

Table 3Intention To Receive Test Results

	<u>ALL WOMEN</u>	<u>UNAFFECTED WOMEN</u>	<u>AFFECTED 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 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 saliency of such family issues in the reasons for getting testing. Moreover, now that it has been decided that testing is appropriate for unaffected women only when they are members of families with known mutations, the saliency of family issues for affected women is likely to increase.

Table 4

Reasons For Seeking Testing

	<u>ALL WOMEN</u>	<u>UNAFFECTED WOMEN</u>	<u>AFFECTED WOMEN</u>
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	15.1	13.2
	*p<.05	**p<.01	***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.

Table 5

Perceived Likelihood Of Breast Cancer

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

Baseline Distress and Psychiatric Morbidity

As we noted, one of our objectives for the first year was 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 data concerning intention to get test results and cancer worries. In the second year, we have modified our earlier results based on continued accrual of subjects, although the pattern of remarkably low distress and psychiatric morbidity remains. Additionally, we completed sophisticated analyses of the performance of screening instruments. As dictated by the low preference of psychiatric disorder, the positive predictive value of positive screening for distress is quite low. Practically speaking, screening for psychiatric morbidity is not needed or efficient.

Cancer worries. 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 items 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).

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).

Current Depression, Anxiety, and Alcohol Use Disorders and History of Depression.

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 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 modularized 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.

Table 6 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 6

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

Table 7 presents some new analyses of the MOS SF-36 data for the unaffected and affected women. As can be seen, the women did not differ for any of the SF-36 scales. Moreover, they exceed normative data for all scales. These data offer further corroboration of our previous findings that our combined sample is an exceptionally well adapted group of women.

Table 7

Mean Scores Of Physical And Mental Health Functioning For Women Affected And Unaffected By Cancer

<u>SF-36 SCALES</u>	<u>UNAFFECTED WOMEN</u>	<u>AFFECTED WOMEN</u>	<u>t</u>
Physical Functioning	87.89	84.90	1.57
Social Functioning	86.20	85.74	.24
Role-Emotional	83.02	82.18	.28
Role-Physical	80.89	76.36	1.37
Mental Health	74.61	74.39	.16
General Health	72.72	69.67	1.62
Bodily Pain	72.43	73.98	-.68
Vitality	59.96	59.27	.35

*p<.05, **p<.01, ***p<.001

Note: Scores range from 0-100 with higher scores indicating a better health state.

Table 8(next page) presents the results obtained with the Hopkins Symptom Checklist. These results have changed only slightly with the accrual of more women. Interpretation of these results is assisted by making a comparison with our HSCL-25 data obtained with other samples, presented in Table 9(next page). Our sample, both affected and unaffected, is remarkably free of distress. This disconfirms expectations that at risk women seeking testing are a highly distressed group.

TABLE 8
Psychological Distress

	<u>All Women</u>	<u>Affected Women</u>	<u>Unaffected Women</u>
Hopkins-25	37.5 (9.2)	37.8 (9.2)	37.3 (9.0)
% in Clinical Range (Greater Than 43)	23%	22%	24%

Table 9
Psychological Distress In Other Samples

Cohen, Coyne, Duvall (1993):

Adoptive Nonclinical Mothers	34.52 (7.09)
Biological Nonclinical Mothers	36.25 (8.9)
Adoptive Clinical Mothers	43.64 (12.3)
Biological Clinical Mothers	41.30 (12.1)

Coyne & Smith (1991)

Wives of Post-MI Patients	41.8 (10.2) 32%
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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)
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Table 10 presents the updated 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.

TABLE 10

Psychiatric Morbidity

	<u>All Women</u>	<u>Affected Women</u>	<u>Unaffected Women</u>
Current Major Depression	5 (1%)	4 (2%)	1 (.4%)
Lifetime Major Depression	87 (18%)	46 (21%)	41 (16%)
Current Major Depression (GMC)	2 (.4%)	2 (.4%)	0
Lifetime Major Depression (GMC)	10 (2%)	7 (3%)	3 (1%)
Generalized Anxiety Disorder	3 (.6%)	1 (.5%)	2 (.8%)
Mixed Anxiety Depression	3 (.6%)	0	3 (1%)
Dysthymia	2 (.4%)	1 (.5%)	1 (.4%)
Alcohol Use Current	1 (.2%)	0	1 (.4%)

Performance of Screening Instruments

Table 11 (next page) presents results of our analysis of the performance of the HSCL-25 as a screening instrument. As we noted, the performance of these instruments in detecting disorder in this study was constrained by the low prevalence (Elwood, 1993). A score meeting or exceeding the clinical cut-point of 44 on the HSCL-25 yielded a sensitivity of 80%, a specificity of 80%, and a positive predictive value of 4% for depression. The respective values for the HSCL-25 with generalized anxiety as the criterion were 100%, 79%, and 3%. The respective values for the HSCL-25 with either depression or generalized anxiety as the criterion were 88%, 93%, and 7%. We also examined the performance of some simple screening questions tapping two weeks mood disturbance and impairment in functioning due to mood. Women's self-report on a 2-weeks mood disturbance screening question yielded a sensitivity of 60%, a specificity of 86%, and a positive predictive value of 5% for major depression. Little difference was found for including the requirement of a report of impairment for the 2-weeks mood disturbance in the form of seeking treatment or experiencing difficulties in interpersonal functioning.

Thus, we found that a low score on a standardized measure of distress was a good indicator that the women were not suffering from major depression or from an anxiety disorder. Yet persons scoring above a standard cut-point were unlikely to meet criteria for a clinical disorder, indicating that the measure had low positive predictive value. All self-report measures designed to screen for depression and anxiety are plagued by poor performance in general medical populations. However, the positive predictive value of 4% for major depression in the present study is still a fraction of the 15-30% obtained in primary care populations (Fechner-Bates et al. 1994; Hough et al. 1982). Indeed, a woman screening positive for depression on the self-report measure in the present sample would still only be as likely to be depressed as a randomly selected, unscreened woman in the general medical population (Coyne et al. 1994, Katon & Schulberg, 1992). What these results demonstrate is that as a group, the women do not require extensive psychological screening and diagnostic assessment. The use of screening instruments would be inefficient in that the vast majority of women who were distressed would not meet criteria for a clinical disorder.

TABLE 11
Performance of HSCL-25 as a Screening Measure

	<u>Sensitivity</u>	<u>Specificity</u>	<u>Positive Predictive Value</u>
Elevated HSCL-25 and Depression	.80	.8	.04
Elevated HSCL-25 and GAD	1.0	.81	.03
Elevated HSCL-25 and Either	.88	.8	.07

Social Support Processes

Table 12 presents results concerning the role of husbands and sisters in decision making about risk of breast cancer. It is clear across items that husbands have more of a role in decision making than sisters do, and that the women are at least as satisfied with their participation as with their sisters' participation. Thus, evidence does not favor the notion that the shared high risk status of these women would shift such social support processes toward a greater emphasis on the female relatives and a decreased emphasis on the spouse.

Table 12
Social Support Processes

<u>Likert-Scale Items</u>	<u>Spouse</u> M (SD)	<u>Sister</u> M (SD)
Discuss breast cancer with him/her	2.84 (.92)	2.64 (.93)**
Satisfaction with these discussions	3.23 (.86)	3.20 (.91)
Discuss BRCA1 with him/her	3.02 (1.03)	2.67 (1.16)***
Importance of his/her opinion in your getting BRCA1 testing	2.93 (1.14)	2.37 (1.25)***
Importance of his/her opinion in making decisions about reducing risk	3.11 (1.12)	2.49 (1.19)***

* $p < .05$, ** $p < .01$, *** $p < .001$

Table 13 presents bivariate relationships among psychological distress, breast cancer worries, and social support. As can be seen, social support is a key determinant of levels of distress. In particular, for married unaffected women the simple bivariate relationship between marital satisfaction and distress is as great as the effect of breast cancer worries.

Table 13

Bivariate Pearson Correlations Of Distress, Marital Adjustment, And Support Variables For Married Women¹

	1	2	3	4	5	6	7
1. Hopkins	1.00	NA	-.44***	-.22**	.30***	-.22**	.14
2. Breast Cancer Worry	.30***	1.00	NA	NA	NA	NA	NA
3. DAS	-.35***	-.11	1.00	.50***	-.44***	.19*	-.10
4. Spouse Support	-.08	-.04	.52***	1.00	-.51***	.36***	-.14
5. Spouse Unsupportive	.25***	.04	-.51***	-.53***	1.00	.00	.21*
6. Sister Support	-.16*	-.10	.03	.21**	-.06	1.00	-.35***
7. Sister Unsupportive	.13	.11	-.09	-.02	.21**	-.54***	1.00

* $p < .05$, ** $p < .01$, *** $p < .001$

¹Affected women are above the diagonal and unaffected women are below.

Table 14 presents results of regression analyses shedding more light on the relative importance of social support processes and breast cancer worries. As can be seen, social support plays more of a role in the distress levels of these women than does breast cancer worries. Negative involvement from spouses and positive involvement from sisters matter most.

Table 14

Hierarchical Regression Examining Relation of Positive and Negative Support to Psychological Distress with Controls for Demographics and Breast Cancer Worries.

<u>Predictor Variables</u>	<u>Change in R2</u>	<u>B</u>
Step 1: Demographic Variables	.03	
Age		.003
Breast Cancer Status		.22**
Time since Diagnosis ^a		-.20*
Step 2: Breast Cancer Worries ^b	.04**	.45**
Step 3: Spouse Support	.08***	
Positive Behaviors		.05
Negative Behaviors		.30***
Step 4: Female Family Member Support	.03*	
Positive Behaviors		-.18**
Negative Behaviors		-.02
Full Predictor Set	R2 = .17***	

^a Only entered for affected women. ^b Only entered for unaffected women; affected women were not asked this question.

* $p < .05$; ** $p < .01$; *** $p < .001$.

DISCUSSION

At their baseline assessment prior to being offered genetic testing, both women affected and yet unaffected by breast cancer were remarkably free 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 that 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. Our data do not support this idea. Our findings of a lack of morbidity were based on validated measures of self-reported distress and carefully constructed clinical 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 a more charitable explanation of the low levels of distress and impairment in high risk women. We 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.

In our second year, these results have been sustained with continued accrual of women in our sample and we have had additional findings related to the performance of screening instruments and the role of social support processes in the lives of these women. Our results do not suggest the utility of routine screening of these women for psychiatric morbidity. As seen in low positive predictive values, the exceptionally poor performance of screening instruments is dictated by the low prevalence of psychiatric disorder.

It should be pointed out that ours is the only study of women from hereditary breast cancer registries which incorporates interview-based ascertainment of psychiatric diagnosis. Other studies rely exclusively on self-report. Our results suggest that not only are these women low in distress but, as seen in our analysis of the performance of measures of distress, these self-report measures are poor indicators of psychiatric disorder. This suggests that other investigators should be careful not to over interpret the clinical significance of distress in their sample. Indeed, what distress is to be found may represent adaptive worrying, rather than maladjustment.

Our findings concerning social support processes were not entirely anticipated. The women are satisfied with the support they receive and this support contributes to their adjustment. However, despite their shared risk status, female relatives are less involved than husbands in decision-making. The practical implications of this finding are that it is important to include husbands in counseling and education because it is crucial that they be adequately informed and prepared for the role they play in their wives' decisions. Finally, our multivariate analyses put breast cancer worries of these women in a larger perspective. Despite their high risk status, social support processes remain a key determinant of their adjustment. Such processes may be important to their overall positive adjustment. It remains to be seen if women in the community seeking testing similarly have the benefits of such support.

We remain concerned about the generalizability of our findings and those of other investigations of high risk women drawn from registry samples. Members of high risk families jointly participate in these registries, and they typically have marshaled considerable social support to manage their shared sense of being at high risk for cancer. Participation in these registries has also given these women exceptional opportunities to become informed about their risk of cancer and genetic testing, to come to terms with their risk status, and to evaluate the advantages and disadvantages of testing for themselves and their families.

In contrast, women from the community seeking testing are likely to be less socially advantaged and less informed or psychologically prepared for the dilemma of whether to proceed with testing. For these women, the decision to pursue testing may be precipitous and tied to recent stressors such as a positive mammography or the diagnosis or death of a family member. Pre-existing psychological distress may impair these women's efforts to become educated and to decide on the merits of testing for them. They may be naive about the issues of insurance and social discrimination associated with being known to have an altered gene. Social support related to being at high risk and to deciding about testing may be deficient or absent. Without appropriate services there is the prospect of these women may obtain testing without being adequately informed consent and they may experience negative psychosocial consequences without achieving the intended benefits of testing. Yet, at the present time, we lack the knowledge base needed to specify just what are appropriate services. Results from our community studies will address this need for a better understanding of women in the general population seeking testing. The intent of this work is to generate data having direct and immediate application in the refining and evaluating of urgently needed clinical protocols..

CONCLUSION

As noted in last year's report, our project made substantial progress in the first year in its implementation, confronting of a variety of 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 shifted 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 produced data from our affected women which are optimistic concerning the mental health of longer term cancer survivors.

In our second year, we have produced results arguing against the utility of routine screening of these women for psychiatric morbidity. Furthermore, we showed that other investigators who do not have the benefit of interview-based assessment of psychiatric disorder should be cautious in interpreting distress among high risk women as psychopathology. We have also shown the relative importance of social support processes in the lives of these women, and in particular the role of the spouse for married women.

Looking forward to our third year, we will have the benefit of data resulting from the progression of these women through the opportunity to obtain testing and into the follow up phase of the study. Furthermore, we will have important comparison data from community samples.

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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 Affected and Unaffected versions)
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 (Brother and Sister Versions)
Proband Post-Results Questionnaire-1 (4-8 weeks)
Proband Post-Results Questionnaire-2 (6 Months)

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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?

A9. What is the highest level of education you have completed? (Check 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 following two questions are optional, but we hope that you will provide this information. Please check the appropriate box.

A10. What is your 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 B

B1. Have you ever been diagnosed with breast cancer? Yes No

B2. Have you ever been diagnosed with ovarian cancer? Yes No

B3. Have you ever had any of the following surgical procedures? (Please check all that apply).

_____ Lumpectomy (Removal of lump from breast) _____ Oophorectomy (Removal of ovaries)

_____ Unilateral mastectomy (Removal of one breast) _____ Hysterectomy (Removal of uterus)

_____ Bilateral mastectomy (Removal of both breasts)

B4. Compared to the average woman, how likely are you to develop breast cancer?

	Much Less				Much More
	Likely				Likely
	1	2	3	4	5

B5. Compared to other women in your family, how likely are you to develop breast cancer? Much Less Likely 1 2 3 4 5 Much More Likely

B6. Overall, what do you believe your risk to be of developing breast cancer in the near future?

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

B7. Overall, what do you believe your risk to be of developing breast cancer at some point in your lifetime?

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

B8. A medical test may soon be available that allows some individual women to learn their risk for developing a form of breast and ovarian cancer that runs in families. Knowing this, what is your intention concerning this test at the present time? (**Please check one response**).

- I will definitely take the test immediately when it becomes available.
- I will definitely take the test, but I am not sure if immediately.
- I will probably take the test immediately when it becomes available.
- I will probably take the test, but not immediately.
- I am undecided whether I will take 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 not** think you will probably or definitely take the test, what are your reasons for **not** doing so? (**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?

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>	
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?

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>	
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

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>	
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?

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>	
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
l.	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

		<i>Not At All</i>			<i>All The Time</i>	
		1	2	3	4	5
B15.	How often do you worry about developing breast cancer?					
B16.	To what extent do any worries you have about breast cancer interfere with every day life?					

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 **first column**, please keep in mind the female family member at similar risk for breast cancer **with whom you are closest**. Answer the questions in the **second column** keeping in mind **your spouse or intimate partner**. If you do not have a spouse or intimate partner, please leave the second column blank. For the **third column**, please keep in mind **another family member or friend to whom you are closest**.

	Female Family Member at Risk for Breast Cancer	Spouse/Partner	Another Family Member/Friend
C1. Was physically present when you needed them.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C2. Told you what he/she did in a similar situation.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C3. Did activities to help you get your mind off things.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C4. Told you that the things you talk about are private--just between the two of you.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C5. Suggested some action you should take.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C6. Comforted you by showing you physical affection.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C7. Listened to you talk about your private feelings.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C8. Agreed that what you want to do is right.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C9. Told you how he/she felt in a similar situation.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C10. Let you know that he/she will always be around if you need assistance.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No

	<u>Female Family Member at Risk for Breast Cancer</u>	<u>Spouse/Partner</u>	<u>Another Family Member/ Friend</u>
C11. Gave you feedback on how you were doing without saying it was good or bad.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C12. Pitched in and helped you do things that needed to get done.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C13. Intruded into your personal feelings and concerns.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C14. Gave you unsolicited advice.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C15. Attempted to make unwanted contact.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C16. Discouraged you from discussing your feelings and concerns.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C17. Minimized your worries or concerns.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C18. Rejected you for displaying emotional upset.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C19. Insisted that you remain upbeat and optimistic.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C20. Let you down when you were counting on him/her.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No

C21. Is there anyone in your life with whom you can share your most private feelings without holding back?
 yes no

C21a. **If you are married or living with a partner**, can you share your most private feelings with this partner without holding back?
 yes no

D1. Have any of the events listed happened to you in the past six months? (**Check All That Apply**)

- | | |
|---|--|
| a. <input type="checkbox"/> You retired or were fired or laid off from work. | g. <input type="checkbox"/> A close family member was seriously ill or injured. |
| b. <input type="checkbox"/> You were unemployed and looking for work. | h. <input type="checkbox"/> You had a marital separation or divorce. |
| c. <input type="checkbox"/> Your spouse retired or was fired or laid off from work. | i. <input type="checkbox"/> You had serious troubles with relatives or close friends. |
| d. <input type="checkbox"/> Your spouse was unemployed and looking for work. | j. <input type="checkbox"/> Your spouse had troubles difficulties with relatives or close friends. |
| e. <input type="checkbox"/> You had problems with the police or court. | k. <input type="checkbox"/> A close family member died. |
| f. <input type="checkbox"/> You got into serious financial difficulties. | l. <input type="checkbox"/> A close friend or relative died. |
| | m. <input type="checkbox"/> 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.

		<i>Strongly Disagree</i>		<i>Neutral</i>		<i>Strongly Agree</i>	
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 **twice**. First, please indicate for each word ***how well it describes you*** and second, ***how much it matters to you*** using the following scale.

1 Extremely	2 Very much	3 Somewhat	4 Not very well	5 Not at all
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		<i>DESCRIBES ME</i>					<i>MATTERS TO ME</i>				
		1	2	3	4	5	1	2	3	4	5
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 *in the future*, and then, indicate how important it is for you to see yourself this way *in the future*.

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

		<u>WILL DESCRIBE YOU</u>					<u>IMPORTANT FOR YOU TO SEE YOURSELF THIS WAY IN FUTURE</u>				
		1	2	3	4	5	1	2	3	4	5
G1.	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
G6.	Being a grandmother	1	2	3	4	5	1	2	3	4	5
G7.	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
G9.	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 married or living with a partner. Please complete them if you are. If you are not married or living with a partner, 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	Occasionally Disagree	Frequently Disagree	Almost Always Disagree	Always Disagree
H1.	Handling family finances						
H2.	Matters of recreation						
H3.	Religious matters						
H4.	Demonstration of affection						
H5.	Friends						
H6.	Sex relations						
H7.	Conventionality (correct or proper behavior)						
H8.	Philosophy of life						
H9.	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	Occasionally	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 you 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	Occasionally	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.						

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).**

H29. Being too tired for sex. Yes No

H30. Not showing love. Yes No

H31. 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 statement which best describes the degree of happiness, all things considered, of your relationship.

Extremely Unhappy	Fairly Unhappy	A Little Unhappy	Happy	Very Happy	Extremely Happy	Perfect
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H32. Please check one of the following statements which best describes how you feel about the **future** 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 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.

_____ My relationship can never succeed, and there is no more that I can do to keep the relationship going.

SECTION I

11. In general, would you say your health is:

Excellent Very Good Good Fair Poor

12. 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.*

		<i>YES, limited a lot.</i>	<i>YES, limited a little.</i>	<i>NO, not limited at all.</i>
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.			

14. **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 amount of time you spent on work or other activities.
 Yes No
- b. Accomplished less than you would like.
 Yes No
- c. Were limited in the kind of work or other activities.
 Yes No
- d. Had difficulty performing the work or other activities (for example, it took extra effort).
 Yes No

15. **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)?

- a. Cut down the amount of time you spent on work Yes No
or other activities.
- b. Accomplished less than you would like. Yes No
- c. Didn't do work or other activities as Yes No
carefully as usual.

16. **During the past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

- Not at all Slightly Moderately Quite a bit Extremely

17. How much bodily pain have you had **during the past 4 weeks**?

- Not at all Slightly Moderately Quite a bit Extremely

18. **During the past 4 weeks**, how much did pain interfere with your normal work (including both work outside the home and housework)?

- Not at all Slightly Moderately Quite a bit Extremely

19. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time **during the past 4 weeks**: *Please mark the appropriate box to indicate your response.*

		<i>All of the time</i>	<i>Most of the time</i>	<i>A good bit of the time</i>	<i>Some of the time</i>	<i>A little of the time</i>	<i>None of the time</i>
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?						

		<i>All of the time</i>	<i>Most of the time</i>	<i>A good bit of the time</i>	<i>Some of the time</i>	<i>A little of the time</i>	<i>None of the time</i>
g.	Have you been a happy person?						
h.	Did you feel tired?						

I10. **During the past 4 weeks**, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

- 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

I11. How **TRUE** or **FALSE** is each of the following statements for you?

	<i>Definitely True</i>	<i>Mostly True</i>	<i>Don't Know</i>	<i>Mostly False</i>	<i>Definitely False</i>
a. I seem to get sick a little easier than other people.					
b. I am as healthy as anybody I know.					
c. I expect my health to get worse.					
d. My health is excellent.					

I12. In the **past 6 months**, have you had two weeks or more when nearly every day you felt sad, blue, or depressed or in which you lost all interest in things like work or hobbies or things you usually liked to do for fun?

- YES** **NO**

- a. If **yes**, there was such a two-week period, did your work or relationships suffer?
 yes no
- b. If **yes**, there was such a two-week period, did you get counseling or psychotherapy?
 yes no
- c. If there was such a two-week period, did you get medication for this condition?
 yes no

I13. Are you **currently** receiving counseling or psychotherapy or medication for depression or emotional problems?

- YES** **NO**

- J1. How often do you have a drink containing alcohol?
 Never Monthly or less Two to four times a month
 Two to three times a week Four or more times a week
- J2. How many drinks containing alcohol do you have on a typical day when you are drinking?
 1 or 2 3 or 4 5 or 6 7 to 9 10 or more
- J3. Have you ever felt you should cut down on your drinking?
 YES NO
- J4. Have people annoyed you by criticizing your drinking?
 YES NO
- J5. Have you ever felt bad or guilty about drinking?
 YES NO
- J6. Have you ever taken a drink first thing in the morning to steady your nerves or get rid of a hangover?
 YES NO
- L1. Vividly imagine that you are afraid of the dentist and have to get some dental work done. Which of the following would you do? Check all of the statements that might apply to you.
- ___ 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 imagine that you are being held hostage by a group of armed terrorists in a public building. Which of the following would you do? Check all of the statements that might apply to you.
- ___ 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.
 ___ 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. Vividly 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's has been made and will be announced in several days. 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.

L4. 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 the 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.

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.*

	<i>Not at all</i>	<i>A little</i>	<i>Quite a bit</i>	<i>Extremely</i>
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 energy--slowed 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. Please indicate how much you agree with the following statements.

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>	
		1	2	3	4	5
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.

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>	
		1	2	3	4	5
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.

□ □ □ □ - □



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?

11

Today's Date _____

ID _____

Background Data

A1. Date of Birth _____ Month _____ Day _____ Year _____

A2. Ethnic Background: White Black
 Hispanic Asian
 Native American Other

A3. Religion: Catholic Protestant
 Jewish Other
 None

A4. Are you currently (please check one)?

Single Married
 Not married, but living in a steady, marriage-like relationship Separated
 Divorced Widowed

A5a. If you **are** currently married, what was the date of your current marriage?
 Month _____ Year _____

A5b. Is this your first marriage? Yes No

A6. How many children do you have? _____

A6a1. Ages of DAUGHTERS: a. _____ b. _____ c. _____
 d. _____ e. _____ f. _____

A6a2. Ages of SONS: a. _____ b. _____ c. _____
 d. _____ e. _____ f. _____

A6a. Number of children living at home _____

A6b. Number who are under age 6 _____

A7. Are you currently working for pay outside the home? Yes No

A8. If **yes**, about how many hours per week are you working for pay?
 Less than 10 10-20 21-30 31-40 41 or more

A9. What is the highest level of education you have completed? (Check 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 following two questions are optional, but we hope that you will provide this information. Please check the appropriate box. (Check one)

A10. What is your 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? _____
- B1. When were you first diagnosed with breast cancer? Month _____ Year _____
- B2. Have your lymph nodes been affected?
 Yes No Do Not Know
- B3. Do you currently consider yourself in remission?
 Yes No Do Not Know
- B4. What treatment(s) have you received for breast cancer?
 Chemotherapy Yes No
 Radiation Yes No
 Surgery Yes No
- B5. Have you ever been diagnosed with ovarian cancer? Yes No
 If yes, when? Month _____ Year _____
- B6. Have you ever had any of the following surgical procedures? **(Please check all that apply).**
- B6a. _____ Lumpectomy (Removal of lump from breast)
 If yes, when? Month _____ Year _____
- B6b. _____ Oophorectomy (Removal of ovaries)
 If yes, when? Month _____ Year _____
- B6c. _____ Unilateral mastectomy (Removal of one breast)
 If yes, when? Month _____ Year _____
- B6d. _____ Hysterectomy (Removal of uterus)
 If yes, when? Month _____ Year _____
- B6e. _____ Bilateral mastectomy (Removal of both breasts)
 If yes, when? Month _____ Year _____
- B7. Before your diagnosis of breast cancer, how likely did you think you were to develop breast cancer, compared to the average woman? **(Please circle one)**
 Much Less Likely Much More Likely
 1 2 3 4 5
- B8. Before your diagnosis of breast cancer, how likely did you think you were to develop breast cancer, compared to other women in your family? **(Please circle one)**
 Much Less Likely Much More Likely
 1 2 3 4 5
- B9. Overall, what do you believe your risk is of developing breast cancer *again* **in the near future?**
 0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%
- B10. Overall, what do you believe your risk is of developing breast cancer *again* **at some point in your lifetime?**
 0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%
- B11. Overall, what do you believe your risk is of developing a metasis (cancer spreading to another site) **in the near future?**
 0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

B12. Overall, what do you believe your risk is of developing a metasis **at some point in your lifetime?**

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

B13. Overall, what do you believe your risk is of developing cancer **unrelated** to your breast cancer **in the near future?**

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

B14. Overall, what do you believe your risk is of developing cancer **unrelated** to your breast cancer **at some point in your lifetime?**

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

B15. A medical test may soon be available that allows some women to learn their genetic risk for developing a form of breast and ovarian cancer that runs in families. Even though you have been diagnosed with breast cancer, would you consider taking the genetic test to learn if your cancer is the type that runs in families? (**Please check one response**).

- _____ I will definitely take the test immediately when it becomes available.
- _____ I will definitely take the test, but I am not sure if immediately.
- _____ I will probably take the test immediately when it becomes available.
- _____ I will probably take the test, but not immediately.
- _____ I am undecided whether I will take the test.
- _____ I will probably not take the test.
- _____ I will definitely not take the test.

B16. If you think you will probably or definitely take the test, what are your reasons for doing so? (**Please check all that apply; some may not apply to you**).

- _____ To plan for the future.
- _____ To reduce the uncertainty.
- _____ To know I have to be more careful about doing 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) _____

B17. If you **do not** think you will probably or definitely take the test, what are your reasons for **not** doing so? (**Please check all that apply; some may not apply to you**).

- _____ 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.

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 **first column**, please keep in mind a female family member who may be at risk for breast cancer **with whom you are closest**. Answer the questions in the **second column** keeping in mind **your spouse or intimate partner**. *If you do not have a spouse or intimate partner, please leave the second column blank.* For the **third column**, please keep in mind **another family member or friend to whom you are closest**.

	Female Family Member at Risk for Breast Cancer	Spouse/Partner	Another Family Member/Friend
C1. Was physically present when you needed them.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C2. Told you what he/she did in a similar situation.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C3. Did activities to help you get your mind off things.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C4. Told you that the things you talk about are private--just between the two of you.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C5. Suggested some action you should take.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C6. Comforted you by showing you physical affection.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C7. Listened to you talk about your private feelings.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C8. Agreed that what you want to do is right.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C9. Told you how he/she felt in a similar situation.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C10. Let you know that he/she will always be around if you need assistance.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C11. Gave you feedback on how you were doing without saying it was good or bad.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C12. Pitched in and helped you do things that needed to get done.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C13. Intruded into your personal feelings and concerns.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C14. Gave you unsolicited advice.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C15. Attempted to make unwanted contact.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C16. Discouraged you from discussing your feelings and concerns.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C17. Minimized your worries or concerns.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C18. Rejected you for displaying emotional upset.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C19. Insisted that you remain upbeat and optimistic.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C20. Let you down when you were counting on him/her.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No

C21. Is there anyone in your life with whom you can share your most private feelings without holding back?

Yes

No

C21a. **If you are married or living with a partner**, can you share your most private feelings with this partner without holding back?

- Yes No

D1. Have any of the events listed happened to you in the past six months? (**Check All That Apply**)

- | | |
|---|--|
| a. <input type="checkbox"/> You retired or were fired or laid off from work. | g. <input type="checkbox"/> A close family member was seriously ill or injured. |
| b. <input type="checkbox"/> You were unemployed and looking for work. | h. <input type="checkbox"/> You had a marital separation or divorce. |
| c. <input type="checkbox"/> Your spouse retired or was fired or laid off from work. | i. <input type="checkbox"/> You had serious troubles with relatives or close friends. |
| d. <input type="checkbox"/> Your spouse was unemployed and looking for work. | j. <input type="checkbox"/> Your spouse had troubles difficulties with relatives or close friends. |
| e. <input type="checkbox"/> You had problems with the police or court. | k. <input type="checkbox"/> A close family member died. |
| f. <input type="checkbox"/> You got into serious financial difficulties. | l. <input type="checkbox"/> A close friend or relative died. |
| | m. <input type="checkbox"/> 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.

		Strongly Disagree			Neutral	Strongly Agree	
		1	2	3	4	5	
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 **twice**. First, please indicate for each word ***how well it describes you*** and second, ***how much it matters to you*** using the following scale.

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

		<i>DESCRIBES ME</i>					<i>MATTERS TO ME</i>				
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 *in the future*, and then, indicate how important it is for you to see yourself this way *in the future*.

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

		<u>WILL DESCRIBE YOU</u>					<u>IMPORTANT FOR YOU TO SEE YOURSELF THIS WAY IN FUTURE</u>				
		1	2	3	4	5	1	2	3	4	5
G1.	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
G6.	Being a grandmother	1	2	3	4	5	1	2	3	4	5
G7.	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
G9.	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 married or living with a partner. Please complete them if you are. If you are not married or living with a partner, 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	Occasionally Disagree	Frequently Disagree	Almost Always Disagree	Always Disagree
H1.	Handling family finances						
H2.	Matters of recreation						
H3.	Religious matters						
H4.	Demonstration of affection						
H5.	Friends						
H6.	Sex relations						
H7.	Conventionality (correct or proper behavior)						
H8.	Philosophy of life						
H9.	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	Occasionally	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	Occasionally	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	Occasionally	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.						

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).**

H29. Being too tired for sex. Yes No

H30. Not showing love. Yes No

H31. 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 statement which best describes the degree of happiness, all things considered, of your relationship.**

Extremely Unhappy	Fairly Unhappy	A Little Unhappy	Happy	Very Happy	Extremely Happy	Perfect
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H32. Please check one of the following statements which best describes how you feel about the **future** 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 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.
- _____ 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 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

PLEASE CONTINUE ON TO NEXT PAGE

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.*

		<i>YES, limited a lot.</i>	<i>YES, limited a little.</i>	<i>NO, not limited at all.</i>
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.			

14. **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?

I4a. Cut down the amount of time you spent on work or other activities.

Yes No

I4b. Accomplished less than you would like.

Yes No

I4c. Were limited in the kind of work or other activities.

Yes No

I4d. Had difficulty performing the work or other activities (ie., it took extra effort).

Yes No

15. **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)?
- 15a. Cut down the amount of time you spent on work or other activities. Yes No
- 15b. Accomplished less than you would like. Yes No
- 15c. Didn't do work or other activities as carefully as usual. Yes No
16. **During the past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?
 Not at all Slightly Moderately Quite a bit Extremely
17. How much bodily pain have you had **during the past 4 weeks**?
 Not at all Slightly Moderately Quite a bit Extremely
18. **During the past 4 weeks**, how much did pain interfere with your normal work (including both work outside the home and housework)?
 Not at all Slightly Moderately Quite a bit Extremely
19. These questions are about how you feel and how things have been with you during the past **4 weeks**. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time **during the past 4 weeks**: *Please mark the appropriate box to indicate your response.*

		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?						
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?						
h.	Did you feel tired?						

I10. **During the past 4 weeks**, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

- 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

I11. How **TRUE** or **FALSE** is each of the following statements for you?

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
a. I seem to get sick a little easier than other people.					
b. I am as healthy as anybody I know.					
c. I expect my health to get worse.					
d. My health is excellent.					

I12. In the **past 6 months**, have you had two weeks or more when nearly every day you felt sad, blue, or depressed or in which you lost all interest in things like work or hobbies or things you usually liked to do for fun? Yes No

I12a. If **yes**, there was such a two-week period, did your work or relationships suffer? Yes No

I12b. If **yes**, there was such a two-week period, did you get counseling or psychotherapy? Yes No

I12c. If there was such a two-week period, did you get medication for this condition? Yes No

I13. Are you **currently** receiving counseling or psychotherapy or medication for depression or emotional problems? Yes No

J1. How often do you have a drink containing alcohol?
 Never Monthly or less Two to four times a month
 Two to three times a week Four or more times a week

J2. How many drinks containing alcohol do you have on a typical day when you are drinking?
 1 or 2 3 or 4 5 or 6 7 to 9 10 or more

J3. Have you ever felt you should cut down on your drinking? Yes No

J4. Have people annoyed you by criticizing your drinking? Yes No

J5. Have you ever felt bad or guilty about drinking? Yes No

J6. Have you ever taken a drink first thing in the morning to steady your nerves or get rid of a hangover? Yes No

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.*

	<i>Not at all</i>	<i>A little</i>	<i>Quite a bit</i>	<i>Extremely</i>
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 energy--slowed 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. Vividly imagine that you are afraid of the dentist and have to get some dental work done. Which of the following would you do? Check all of the statements that might apply to you.

_____ 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 imagine that you are being held hostage by a group of armed terrorists in a public building. Which of the following would you do? Check all of the statements that might apply to you.

_____ 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.
 _____ 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. Vividly 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's has been made and will be announced in several days. 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.

- L4. 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 the 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.

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

		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 CONTINUE ON TO NEXT PAGE

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

		Strongly Disagree			Strongly Agree	
		1	2	3	4	5
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.

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Women's Health Study

Telephone Questionnaire

Revised 4/19/96

Introduction/Confidentiality Statement

Hello. My name is _____. I'm calling from the Women's Health Study. Thank you for returning your questionnaire. As we had mentioned, we have some questions about your opinions, experiences, and feelings related to cancer and genetic testing, and about your mood. You may have provided some of this information 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 also like to assure you that this interview is confidential and completely voluntary. If we should come to any questions which you do not want to answer or which do not apply to you, just let me know and we will go on to the next question. For quality control purposes, we would like to tape record this interview if that is all right with you. ...May we begin?

Date _____

Length of IW _____

Length of Edit _____

Interviewer _____

CANCER STATUS:

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 At All Distressing			Very Distressing	
1	2	3	4	5

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

1. Have Been Diagnosed	5. Have Not
------------------------	-------------

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			Very Distressing	
1	2	3	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. No
--------	-------

IF R INDICATES "YES" TO 2d:

2e. When did you receive this second diagnosis?

DATE: _____ (month/year)

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 At All Distressing			Very Distressing	
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. No
--------	-------

IF R INDICATES "YES" TO 2g:

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

TIME: _____ (months)

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 At All Distressing			Very Distressing	
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			Very Distressing	
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

- 2l. 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 Distressing			Very 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 At All Distressing			Very Distressing	
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 BY CANCER:

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

Now I am going to ask you about your experiences with cancer among your close relatives.

Let's Start with _____(relationship)

0. Is she from your mother or your father's side of the family?

Mother's	Father's
1	2

1. When was she diagnosed?

DATE: _____(year)

1a. On a scale from 1 to 5, how distressed were you by her diagnosis?

Not At All Distressed					Very Distressed					Didn't Know IF VOL.	
1	2	3	4	5							6

2. Is she alive?

1. Yes	5. No
---------------	--------------

IF R ANSWERS "NO" TO 2:

2a. Did she die of the cancer or something related to it?
SCORE R's BELIEF

1. Yes	5. No
---------------	--------------

IF R ANSWERS "YES" To 2a:

2b. When did she die?

DATE: _____(year)

2c. How old was she when she died?

AGE: _____(years)

2d. How old were you when she died?

AGE: _____(years)

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

Not At All Distressed			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. No
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.
		1	2	3	4	5	6
4.	At the time of the illness, how (emotionally) close were you to your (relative)?						

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
	1	2	3	4	5	6	
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. No
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.
	1	2	3	4	5	6	
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	No 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.
		1	2	3	4	5	6
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]						

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

11. 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	
		1	2	3	4	5
a.	Your OB/GYN					
b.	Your family physician					
c.	Another physician (Specialty_____)					
d.	Family Members [WHO GAVE INFO]					
e.	Friends [WHO GAVE INFO]					
f.	Newspapers, television, and radio					
g.	Popular women's magazines					
h.	Other (specify_____)					

READ 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?

1. Yes	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 most distressing part?

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

Not At All Distressing			Very 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. 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.		

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

- 16f. 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

- 16g. 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 At All Positive								Extremely Positive	
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

Not At All Negative								Extremely Negative	
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?

READ OPTIONS

Never	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

- 17g. 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 At All Positive								Extremely Positive	
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 At All Negative								Extremely Negative	
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. 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.		

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

- 18f. 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

READ OPTIONS

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

- 18g. 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 At All Positive								Extremely Positive	
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 At All Negative								Extremely Negative	
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?

1. Yes	5. No
--------	-------

- 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

- 19f. 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 At All Positive								Extremely Positive	
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 Negative								Extremely Negative	
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. Undecided [IF VOLUNTEERED]
--------	-------	----------------------------------

FOR ALL WOMEN:

20. If you were to find that you were a carrier for BRCA1, the gene for increased risk of breast cancer, what options would you consider?

[DONE]

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 assess **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

MDE CRITERIA

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

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.

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?

(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.

? 1 2 3 A1

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

(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)

? 1 2 3 A2

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

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

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

? = inadequate information

1 = absent or false

2 = subthreshold

3 =threshold or true

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)...

..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 appetite
_____ weight gain or increased appetite

? 1 2 3 A3

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? Was that nearly every night?)

(4) insomnia or hypersomnia nearly every day

Check if:
_____ insomnia
_____ hypersomnia

? 1 2 3 A6

A7

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 A9

NOTE: CONSIDER BEHAVIOR DURING THE INTERVIEW

Check if:
_____ psychomotor retardation
_____ psychomotor agitation

A10

A11

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?)

..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 = subthreshold

3 = threshold or true

SCID (DSM-IV)

Current MDE (WHS 3/96)

Mood Episodes

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:

_____worthless
_____inappropriate guilt

? 1 2 3 A13

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 decisions about everyday things? (Nearly every day?)

(8) diminished ability to think or concentrate, or indecisiveness, nearly every day (either by subjective account or as observed by others)

check if:
_____diminished ability to think
_____indecisiveness

? 1 2 3 A16

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

NOTE: CODE "1" FOR SELF-MUTILATION W/O SUICIDAL INTENT

Check if:
_____thoughts of own death
_____suicidal ideation
_____specific plan
_____suicide attempt

? 1 2 3 A19

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)

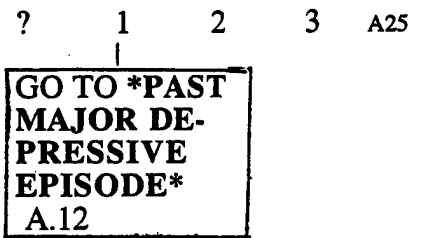
IF UNCLEAR, GO TO PAGE A.1

1 3 A24

GO TO *PAST MAJOR DEPRESSIVE EPISODE*, A.12

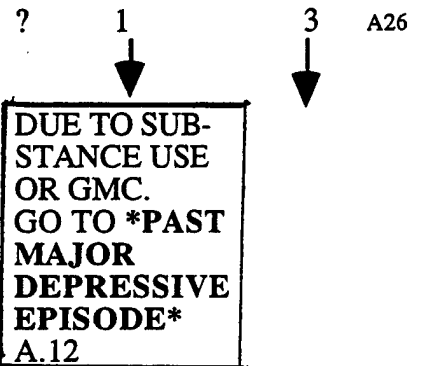
IF UNCLEAR: Has (depressive episode/OWN EQUIVALENT) made it hard for you to do your work, take care of things at home, or get along with other people?

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



Just before this began, were you physically ill?

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



Just before this began, were you taking any medications?

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

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."

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

Etiological general medical conditions include: degenerative neurological illnesses (e.g., 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]

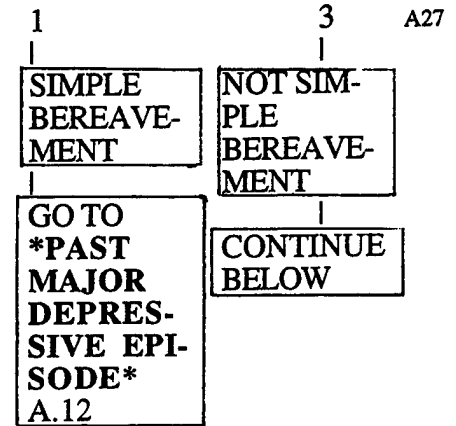
Etiological substances include alcohol, amphetamines, cocaine, hallucinogens, inhalants, opioids, phencyclidine, sedatives, hypnotics, anxiolytics, and other or unknown substances (e.g., steroids)

PRIMARY MOOD EPISODE

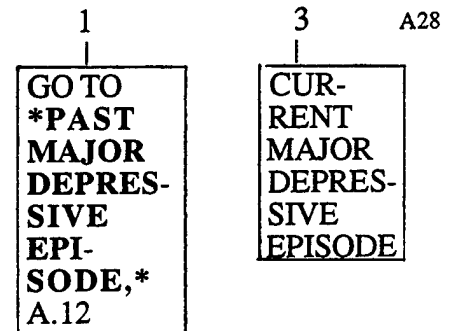
CONTINUE BELOW

(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.



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)?

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

A29

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

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

MDE CRITERIA

-> 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?)

-> 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?)

-> 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?)

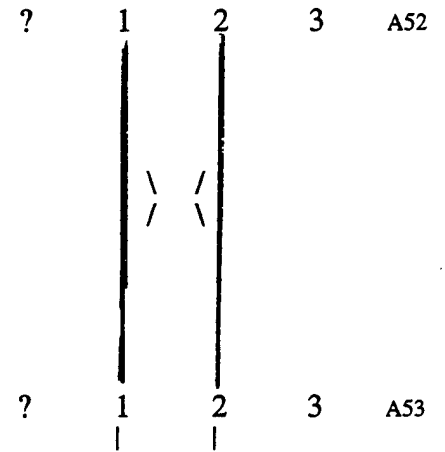
IF UNCLEAR: Have you had any times like that in the past year?

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.



IF NEITHER ITEM (1) NOR (2) IS CODED "3," GO TO *DYSTHYMIA,* A.38

FOR THE FOLLOWING QUESTIONS, FOCUS ON THE WORST TWO WEEKS OF THE PAST MDE YOU ARE EVALUATING. DO NOT EVALUATE A CURRENT MDE.

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

During that (TWO WEEK PERIOD)...

..did you lose or gain any weight? (How much?) (Were you trying to lose weight?)

(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.

? 1 2 3 A54

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?)

Check if:
 _____ weight loss or decreased appetite A55
 _____ weight gain or increased appetite A56

..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? Was that nearly every night?)

(4) insomnia or hypersomnia nearly every day

? 1 2 3 A57

Check if:
 _____ insomnia A58

_____ hypersomnia 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?)

(5) psychomotor agitation or retardation nearly every day (observable by others, not merely subjective feelings of restlessness or being slowed down)

? 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?)

Check if:
 _____ psychomotor retardation A61

_____ psychomotor agitation A62

..what was your energy like? (Tired all the time? Nearly every day?)

(6) fatigue or loss of energy nearly every day

? 1 2 3 A63

? = inadequate information

1 = absent or false

2 = subthreshold

3 = threshold or true

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 :

_____ worthless
_____ inappropriate 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?)

(8) diminished ability to think or concentrate, or indecisiveness, nearly every day (either by subjective account or as observed by others)

check if:
_____ diminished ability to think
_____ indecisiveness

? 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?

(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

NOTE: CODE "1" FOR SELF-MUTILATION W/O SUICIDAL INTENT

Check if:
_____ thoughts of own death
_____ suicidal ideation
_____ specific plan
_____ suicide attempt

? 1 2 3 A70

A71
A72
A73
A74

AT LEAST FIVE OF THE ABOVE SXS [A(1-9)] ARE CODED "3" AND AT LEAST ONE OF THESE IS ITEM (1) OR (2)

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?

-> 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 distress or impairment in social, occupational, or other important areas of functioning.

?

1

2

3...A76

CON-TINUE

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.

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

? = inadequate information

1 = absent or false

2 = subthreshold

3 = threshold or true

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?

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

? 1
DUE TO SUBSTANCE USE OR GMC

3 A77

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)?

PRIMARY MOOD EPISODE

CONTINUE

> 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.

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

(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 BEREAVEMENT

AT LEAST ONE MAJOR EPISODE NOT SIMPLE BEREAVEMENT

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 DYSTHYMIA* A.38

CONTINUE

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

1
GO TO *CURRENT DYSTHYMIA* A.38

3 A79
PAST MAJOR DEPRESSIVE 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

? = inadequate information

1 = absent or false

2 = subthreshold

3 = threshold or true

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)**

DYSTHYMIC DISORDER CRITERIA

-> 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?)

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
*ALCOHOL
USE
DISORDERS*
E.1

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?)

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

Mo/Yr: ____ / ____ Age: ____

-> FOR A PAST MAJOR DEPRESSIVE EPISODE DURING THE PAST TWO YEARS: Let's review when you first had most of the symptoms of (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?

FIRST MET CRITERIA FOR 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: ____

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?)

During these periods of (OWN EQUIVALENT FOR CHRONIC DEPRESSION), do you often...

B. Presence, while depressed, of two (or more) of the following:

...lose you appetite?(What about overeating?)

(1) poor appetite 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 or feel tired a lot?

(3) low energy or fatigue

? 1 2 3 A166

...feel down on yourself? (Feel worthless, or a failure?)

(4) low self-esteem

? 1 2 3 A167

... have trouble concentrating or making decisions?

(5) poor concentration or difficulty making decisions

? 1 2 3 A168

...feel hopeless?

(6) feelings of hopelessness

? 1 2 3 A169

AT LEAST TWO "B" SYMPTOMS CODED "3"

? 1 2 3 A170

GO TO
*ALCOHOL
USE DIS-
ORDERS*
E.1

What is the longest period of time, during this period of long-lasting depression, that you felt ok?(NO DYSTHYMIC SYMPTOMS)

C. During the two year period (one-year for children or adolescents) of the disturbance, the person has never been without the symptoms in A and B for more than two months at a time.

? 1 3 A171

GO TO
*ALCOHOL
USE DIS-
ORDERS*
E.1

NOTE: CODE "1" IF NORMAL MOOD FOR AT LEAST TWO MONTHS AT A TIME

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.

? 1 2 3 A172

GO TO
*ALCOHOL
USE DIS-
ORDERS*
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.

1 3

A174

GO TO
*ALCOHOL USE
DISORDERS* E.1

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

? 1 3 A175

GO TO
*ALCO-
HOL USE
DISORDERS*
E.1

NOT
SUPER-
IMPOSED

CON-
TINUE

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

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 using any street drugs?

G. 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 *SUBSTANCE/GMC* A.43 RETURN HERE AND MAKE RATING OF "1" OR "3"

Etiological general medical conditions include: degenerative neurological illnesses (e.g., 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 known or unknown substances (e.g., steroids).

? 1 3 A176
DUE TO SUBSTANCE USE OR GMC

GO TO *ALCOHOL USE DISORDERS* E.1

PRIMARY MOOD DISORDER

CONTINUE

IF UNCLEAR: How much do your depressed feelings interfere with your life?

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

? 1 3 A177
GO TO *ALCOHOL USE DISORDERS* E.1

DYSTHYMIC DISORDER CRITERIA A, B, C, D, E, F, AND H ARE CODED "3"

1 3 A178
GO TO *ALCOHOL USE DISORDERS* E.1
DYS-THYMIC DIS-ORDER

IF DYSTHYMIC DISORDER Indicate specifier:
1- Early Onset: onset before age 21
2- Late Onset: onset age 21 or older

Specifier: _____ A179

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

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]

? 1 2 3

A188

(2) prominent anxiety, panic
attacks, obsession or compulsions
[FOR ANXIETY]

? 1 3

A189

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

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).

? 1 2 3

A190

GO TO *SUB- STANCE INDUCED* A.45
--

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?

THE FOLLOWING FACTORS
SHOULD BE CONSIDERED
AND SUPPORT THE CONCLU-
SION THAT THE GMC IS ETIO-
LOGIC 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.

? = inadequate information

1 = absent or false

2 = subthreshold

3 = threshold or true

3) THE MOOD/ANXIETY SYMPTOMS 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

? 1 2 3 A191

GO TO
*SUB-
STANCE-
INDUCED*
A.45

D. The disturbance does not occur exclusively during the course of Delirium.

1 3 A192

DELIRIUM
DUE TO A
GMC

MOOD/
ANXIETY
DISORDER
DUE TO A
GMC

RETURN TO EPISODE
BEING EVALUATED

SUBSTANCE -INDUCED MOOD/ANXIETY DISORDER

SUBSTANCE-INDUCED MOOD/ANXIETY DISORDER CRITERIA

EPISODE BEING EVALUATED:	
Current MDE	A.1
Past MDE	A.12
Dysthymia	A.38
Current GAD	F.31
MAD	J.8

IF SYMPTOMS NOT TEMPORALLY ASSOCIATED WITH SUBSTANCE, CHECK HERE _____ AND RETURN TO EPISODE BEING EVALUATED.

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.

? 1 2 3 A196

NOT SUBSTANCE INDUCED RETURN TO EPISODE BEING EVALUATED

Do you think your (MOOD/ ANXIETY SXS) are in any way related to your (SUBSTANCE USE)?

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:

? 1 2 3 A197

NOT SUBSTANCE INDUCED RETURN TO EPISODE BEING EVALUATED

IF YES: Tell me how.

ASK ANY OF THE FOLLOWING QUESTIONS AS NEEDED TO RULE OUT A NON-SUBSTANCE-INDUCED ETIOLOGY:

IF UNKNOWN: Which came first, the (SUBSTANCE USE) or the (MOOD/ANXIETY SYMPTOMS)?

1) the mood/anxiety symptoms precede the onset of the Substance Abuse or Dependence

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)

? = inadequate information

1 = absent or false

2 = subthreshold

3 =threshold or true

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?

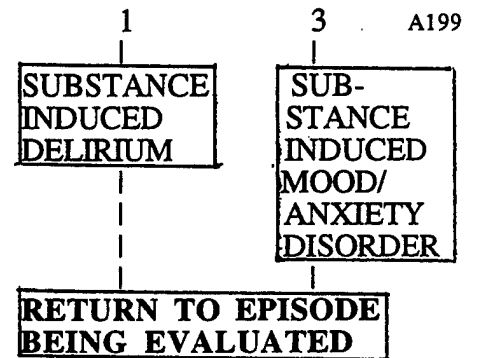
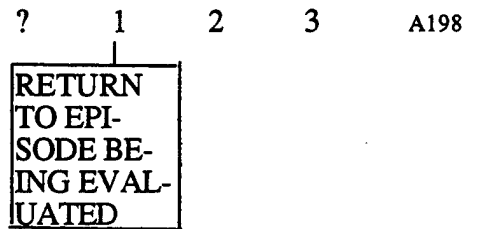
IF UNKNOWN: How much did (MOOD/ANXIETY SYMPTOMS) interfere with your life?

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.

E1

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

LIFETIME ALCOHOL ABUSE

ALCOHOL ABUSE CRITERIA

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

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

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?

(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)

? 1 2 3 E2

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?)

(2) recurrent alcohol use in situations in which it is physically hazardous (e.g., driving an automobile or operating a machine when impaired by alcohol use)

? 1 2 3 E3

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

Has your drinking gotten you into trouble with the law?

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

? 1 2 3 E4

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?)

(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)

? 1 2 3 E5

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

? = inadequate information

1 = absent or false

2 = subthreshold

3 = threshold or true

AT LEAST ONE "A" ITEM
CODED "3"

? 1

3

E6

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

? = inadequate information

1 = absent or false

2 = subthreshold

3 = threshold or true

ALCOHOL DEPENDENCE

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

ALCOHOL DEPENDENCE CRITERIA

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

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?

(4) there is a persistent desire OR unsuccessful efforts to cut down or control substance use

? 1 2 3 E8

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?

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

? 1 2 3 E9

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?

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

? 1 2 3 E10

? = inadequate information

1 = absent or false

2 = subthreshold

3 = threshold or true

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 TWO 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

? 1 2 3 E11

? 1 2 3 E12

? 1 2 3 E13

E14

? = inadequate information

1 = absent or false

2 = subthreshold

3 = threshold or true

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

1

3

E15

ALCOHOL DEPENDENCE

Indicate if:
 1 - With Physiological Dependence (current evidence of tolerance or withdrawal)
 2- Without Physiological Dependence (no current evidence of tolerance or withdrawal)

E16

GO TO DEPENDENCE CHRONOLOGY, E.7

IF ALCOHOL ABUSE QUESTIONS (PAGES E.1-E.3) HAVE NOT 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.

1

3

E17

GO TO *GENERALIZED ANXIETY DISORDER* F.31

ALCOHOL ABUSE

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?

Criteria for Alcohol Abuse met at any time in past month

1

3

E19

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

PAST ABUSE

CUR-RENT ABUSE

GO TO *GENERALIZED ANXIETY DISORDER,* F.31

? = inadequate information

1 = absent or false

2 = subthreshold

3 = threshold or true

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)

— —

E20

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

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

3

E21

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

CUR-
RENT
DE-
PEND-
ENCE

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.)

E22

- 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***

? = inadequate information

1 = absent or false

2 = subthreshold

3 = threshold or true

***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])

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?

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

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)

B. The person finds it difficult to control the worry

F(2). Does not occur exclusively during the course of a Mood Disorder, Psychotic Disorder, or a Pervasive Developmental Disorder

? 1 2 3 F135

GO TO
MIXED ANXIETY DISORDER, J.5

? 1 2 3 F136

GO TO
MIXED ANXIETY DISORDER, J.5

? 1 2 3 F137

GO TO
MIXED ANXIETY DISORDER, J.5

Now I am going to ask you some questions about other symptoms that often go along with being nervous.

C. The anxiety and worry are associated with at least three of the following such symptoms (with at least some symptoms present for more days than not for the past six months) :

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) restlessness or feeling keyed up or on 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) difficulty concentrating or mind going blank

? 1 2 3 F140

... are you often irritable?

(4) irritability

? 1 2 3 F141

...are your muscles often tense?

(5) muscle tension

? 1 2 3 F142

...do you often have trouble falling or staying asleep?

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

? 1 2 3 F143

AT LEAST THREE "C" SXS ARE CODED "3"

1 3 F144

GO TO
*MIXED
ANXIETY
DISOR-
DER,* J.5

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 3 F145

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
DISOR-
DER.* J.5

Just before you began having this anxiety, 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?

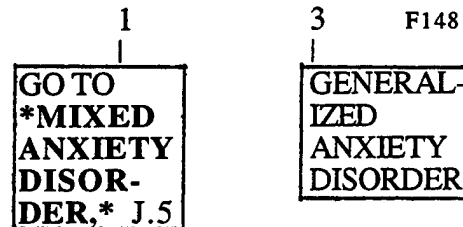
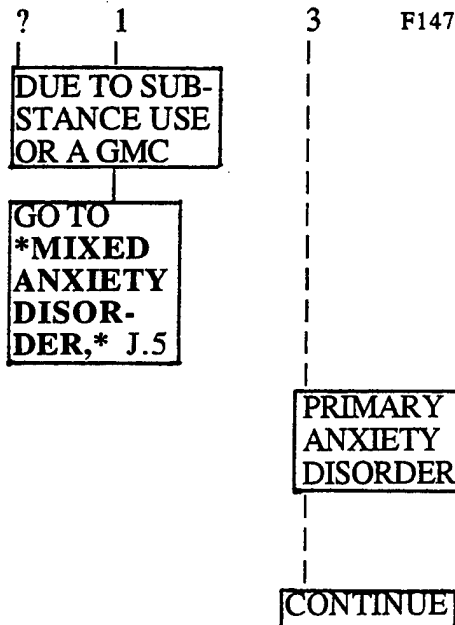
F. Not due to the direct psychological effects of a substance (e.g., a drug of abuse, medication) or to a general medical condition

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.

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.	?	1	2	3	J20
			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	3	J21
...have you had trouble sleeping?	(2) sleep disturbance (difficulty falling or staying asleep, or restless unsatisfying sleep)	?	1	2	3	J22
...have you felt like you were tired all the time or that your energy was low?	(3) fatigue or low energy	?	1	2	3	J23
...have you felt irritable or cranky?	(4) irritability	?	1	2	3	J24
...did you worry a lot about things?	(5) worry	?	1	2	3	J25
...did you find yourself crying over little things?	(6) easily moved to tears	?	1	2	3	J26
...have you been watchful or on guard even when there is no reason to be?	(7) hypervigilance	?	1	2	3	J27

? = inadequate information 1 = absent or false 2 = subthreshold 3 = threshold or true

...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 J29

...did you feel down on yourself or that you were worthless?

(10) low self-esteem or feelings of worthlessness

? 1 2 3 J30

AT LEAST FOUR "B"
SYMPTOMS CODED "3"

? 1 3 J31

|
DONE

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

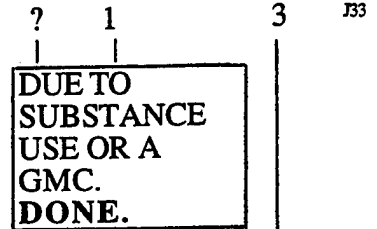
|
|
|
DONE

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, arrhythmias, 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.

PRIMARY ANXIETY DISORDER

CONTINUE

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)

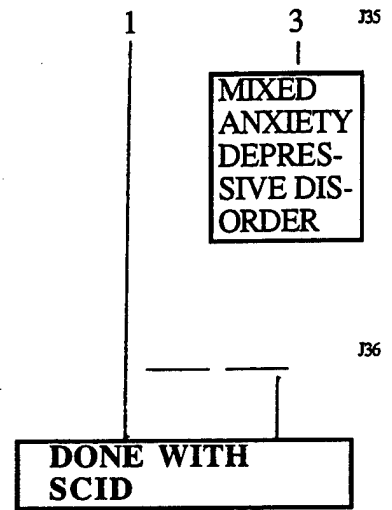
(3) Not better accounted for by any other mental disorder

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

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)

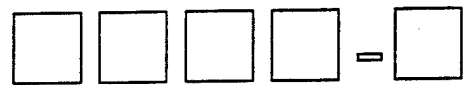


? = inadequate information

1 = absent or false

2 = subthreshold

3 = threshold or true



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

TODAY'S DATE _____

ID _____

INTERIM QUESTIONNAIRE - A

GENETIC TESTING-SECTION 1

1. Have you contributed a blood or tissue sample to the GENETIC TESTING portion of the research project?
 Yes No **B21.**

2. Has any member of your family contributed a blood or tissue sample to the GENETIC TESTING portion of the research project?
 Yes No I Don't Know **B22.**

3. Have you or any family members received notification that genetic results are available? **B23.**

There Has Been No Notification	Results Are Available	Results Are NOT YET Available	Results will NEVER BE Available, I am Not Eligible

4. Have you received results of genetic testing for breast or ovarian cancer?
 Yes No (Skip to Question 5)

4a. When did this occur? _____(mo/yr)

4b. What was the source of this information?
 University of Pennsylvania Independent Testing Other: _____

4c. What were the results? (Optional)

5. Has any family member received results of genetic testing for breast or ovarian cancer?
 Yes No (Skip to Next Section) Don't Know (Skip to Next Section)

5a. When did this occur? _____(mo/yr)

5b. What was the source of this information?
 University of Pennsylvania Independent Testing Other: _____

5c. What were the results? (Optional)

5d. Can you infer your genetic results from your relative's results (i.e., Have you been able to figure out whether you are positive or negative for the gene that conveys higher risk for breast cancer with this information?)
 Yes No Don't Know

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.

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		
		1	2	3	4	5	
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.
l.	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.
o.	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. A medical test may soon be available that allows some women to learn their genetic risk for developing a form of breast and ovarian cancer that runs in families. Even though you have been diagnosed with breast cancer, would you consider taking the genetic test to learn if your cancer is the type that runs in families?
(Please check one response).

B15.

- (1)._____ I will definitely take the test immediately when it becomes available.
 (2)._____ I will definitely take the test, but I am not sure if immediately.
 (3)._____ I will probably take the test immediately when it becomes available.
 (4)._____ I will probably take the test, but not immediately.
 (5)._____ I am undecided whether I will take the test
 (6)._____ I will probably not take the test.
 (7)._____ I will definitely not take the test.

2. On the following scale, indicate how distressing it is for you to know that you may be at increased risk for breast cancer because of your family history?

B66.

Not At All Distressing					Very Distressing	
1	2	3	4	5		

3. How distressing it is to be given the opportunity to be tested for the BRCA-1 gene, the altered gene associated with increased risk for breast cancer?

B67.

Not At All Distressing					Very Distressing	
1	2	3	4	5		

4. How distressed do you expect to be when you actually get tested for the BRCA-1 gene (before you receive results)?

B68.

Not At All Distressed					Very Distressed	
1	2	3	4	5		

5. How distressed would you be if you took the test and found that you **had** the BRCA-1 gene?

B69.

Not At All Distressed					Very 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? B70.

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.

Not At All					Very Much So	
1	2	3	4	5		

		<i>Not At All</i>			<i>All The Time</i>		
		1	2	3	4	5	
8.	How often do you worry about again developing breast cancer?						B27.
9.	To what extent do these worries interfere with your every day life?						B28.
10.	How often do you worry about having the altered gene carrying risk for breast cancer ?						B29.
11.	To what extent do these worries you have about having this altered gene interfere with your every day life?						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 Less Likely					Much More Likely	
1	2	3	4	5		

13. When was the last time you had a mammography? B32.
 _____Month _____Year (-8) This question does not apply because of surgery.

14. How many times have you conducted a breast self-examinations (BSE) in the past six months? B33.

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

15. How confident are you that you will perform breast self examination (BSE) ---

15a. --as **frequently** as needed? (-8) Does Not Apply Because of Surgery B34a.

Not at All 3 4 5 6 7 Very Much So

1 2 3 4 5 6 7

15b. --as **carefully and competently** as needed? B34b.
 (-8) Does Not Apply Because of Surgery

Not at All 3 4 5 6 7 Very Much So

1 2 3 4 5 6 7

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

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

		<u>Have been affected by being at risk for breast cancer</u>					<u>Would be affected by the results of genetic testing</u>					
		1	2	3	4	5	1	2	3	4	5	
16.	Decisions about having children	1	2	3	4	5	1	2	3	4	5	B3
17.	Decisions about form of birth control	1	2	3	4	5	1	2	3	4	5	B3
18.	Decisions about which steps to take to prevent the recurrence of breast cancer	1	2	3	4	5	1	2	3	4	5	B3
19.	Decisions about work and career	1	2	3	4	5	1	2	3	4	5	B3
20.	Decisions about savings and financial planning	1	2	3	4	5	1	2	3	4	5	B3
21.	Decisions about plans for the future	1	2	3	4	5	1	2	3	4	5	B3

22. Answer the following question only if you have (biological) daughters.

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

B41.

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

LIFE EVENTS SECTION

1. Have any of the following events happened to you in the past six months?
(Check All That Apply).

D1(a-m)

- | | |
|---|---|
| <p>a. <input type="checkbox"/> You retired, were fired, or laid off from work.</p> <p>b. <input type="checkbox"/> You were unemployed and looking for work.</p> <p>c. <input type="checkbox"/> Your spouse retired, was fired, or laid off from work.</p> <p>d. <input type="checkbox"/> Your spouse was unemployed and looking for work.</p> <p>e. <input type="checkbox"/> You had problems with the police or court.</p> <p>f. <input type="checkbox"/> You got into serious financial difficulties.</p> | <p>g. <input type="checkbox"/> A close family member was seriously ill or injured.</p> <p>h. <input type="checkbox"/> You had a marital separation or divorce.</p> <p>i. <input type="checkbox"/> You had serious troubles with relatives or close friends.</p> <p>j. <input type="checkbox"/> Your spouse had troubles or difficulties with relatives or close friends.</p> <p>k. <input type="checkbox"/> A close family member died.</p> <p>l. <input type="checkbox"/> A close friend or relative died.</p> <p>m. <input type="checkbox"/> You were seriously ill or injured.</p> |
|---|---|

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

Ha.

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.

		<i>Always Agree</i>	<i>Almost Always Agree</i>	<i>Occasionally Disagree</i>	<i>Frequently Disagree</i>	<i>Almost Always Disagree</i>	<i>Always Disagree</i>	
1.	Religious matters	6	5	4	3	2	1	H3.
2.	Demonstration of affection	6	5	4	3	2	1	H4.
3.	Sex relations	6	5	4	3	2	1	H6.
4.	Conventionality (correct or proper behavior)	6	5	4	3	2	1	H7.
5.	Making major decisions	6	5	4	3	2	1	H12.
6.	Career decisions	6	5	4	3	2	1	H15.

		<i>All of the time</i>	<i>Most of the time</i>	<i>More often than most</i>	<i>Occasionally</i>	<i>Rarely</i>	<i>Never</i>	
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.

		<i>All of Them</i>	<i>Most of Them</i>	<i>Some of Them</i>	<i>Very few of Them</i>	<i>None of Them</i>
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?

		<i>Never</i>	<i>Less than once a month</i>	<i>About twice a month</i>	<i>About twice a week</i>	<i>Once a day</i>	<i>More Often</i>
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 At All Positive									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 At All Negative									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.

		<i>Never</i>					<i>Very Often</i>	
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		H35c.
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, family or group sessions to become informed about your risk for breast cancer and what can be done? H36.

(1) Yes (5) No

19. How much contact has your husband/partner had with medical personnel concerning your risk for breast cancer. H37.

Very Little or None A lot

1 2 3 4 5 6 7

20. Do you feel your husband/partner is adequately informed concerning your risk for breast cancer and what can be done about it? H38.

Not at All Very Much

1 2 3 4 5 6 7

21. To what extent are you satisfied with your husband/partner's involvement in your health care? H39.

Not at All Very Much

1 2 3 4 5 6 7

MOOD SECTION

1. Have you **ever in your lifetime** had two weeks or more when nearly every day you felt sad, blue, or depressed or in which you lost all interest in things like work or hobbies or things you usually liked to do for fun? I14
- (1) Yes (5) No (Skip to Question 2)
- 1a. If there was such a two-week period, did your work or relationships suffer? I14a.
- (1) Yes (5) No
- 1b. If there was such a two-week period, did you get counseling or psychotherapy? I14b.
- (1) Yes (5) No
- 1c. If there was such a two-week period, did you get medication for this condition? I14c.
- (1) Yes (5) No
-
2. In **the past 6 months**, have you had two weeks or more when nearly every day you felt sad, blue, or depressed or in which you lost all interest in things like work or hobbies or things you usually liked to do for fun? I12.
- (1) Yes (5) No (Skip to Question 3)
- 2a. If there was such a two-week period in **the past 6 months**, did your work or relationships suffer? I12a.
- (1) Yes (5) No
- 2b. If there was such a two-week period in **the past 6 months**, did you get counseling or psychotherapy? I12b.
- (1) Yes (5) No
- 2c. If there was such a two-week period in **the past 6 months**, did you get medication for this condition? I12c.
- (1) Yes (5) No
-
3. Are you **currently** receiving counseling, psychotherapy or medication for depression or emotional problems? 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 Past Three Months.*

		<u>Not at all</u>	<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	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 energy--slowed 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 positively by your risk of breast cancer.

		<i>Not At All</i>	<i>A Very Small Degree</i>	<i>A Small Degree</i>	<i>A Moderate Degree</i>	<i>A Great Degree</i>	<i>A Very Great Degree</i>	
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	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>I haven't been doing this at all</i> 1	<i>I've been doing this a little bit</i> 2	<i>I've been doing this some</i> 3	<i>I've been doing this a lot</i> 4	
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 the 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.
l.	I've been trying to come up with a strategy about what to do.	1	2	3	4	L7l.
m.	I've been getting comfort and understanding from someone.	1	2	3	4	L7m.

		<i>I haven't been doing this at all 1</i>	<i>I've been doing this a little bit 2</i>	<i>I've been doing this some 3</i>	<i>I've been doing this a lot 4</i>	
n.	I've been giving up the attempt to cope.	1	2	3	4	L7n.
o.	I've been accepting the possibility that I might have the gene.	1	2	3	4	L7o.
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 might have the 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.

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

L8.

		<i>I haven't been doing this at all 1</i>	<i>I've been doing this a little bit 2</i>	<i>I've been doing this some 3</i>	<i>I've been doing this a lot 4</i>	
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: Catholic (1) Protestant (4) **A3.**
Jewish (2) Buddhist (5)
Muslim (3) Other (6)
None (7)

- 1a. How often do you attend religious services? **A3a.**
(1) (5)
 Less Often Than Once a Month A Few Times A Month or More

- 1b. How important are religious and spiritual beliefs in your life? **A3b.**
Not at All 2 3 4 Very Important
1 5

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

0199-A



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

TODAY'S DATE _____

ID 199-A

INTERIM QUESTIONNAIRE - U

GENETIC TESTING-SECTION 1

1. Have you contributed a blood or tissue sample to the GENETIC TESTING portion of the research project?

Yes No B21.

2. Has any member of your family contributed a blood or tissue sample to the GENETIC TESTING portion of the research project?

Yes No I Don't Know B22.

3. Have you or any family members received notification that genetic results are available? B23.

There Has Been No Notification	Results Are Available	Results Are NOT YET Available	Results will NEVER BE Available, I am Not Eligible

4. Have you received results of genetic testing for breast or ovarian cancer?

Yes No (Skip to Question 5)

4a. When did this occur? _____(mo/yr)

4b. What was the source of this information?

University of Pennsylvania Independent Testing Other: _____

4c. What were the results? (Optional)

5. Has any family member received results of genetic testing for breast or ovarian cancer?

Yes No (Skip to Next Section) Don't Know (Skip to Next Section)

5a. When did this occur? _____(mo/yr)

5b. What was the source of this information?

University of Pennsylvania Independent Testing Other: _____

5c. What were the results? (Optional)

5d. Can you infer your genetic results from your relative's results (i.e., Have you been able to figure out whether you are positive or negative for the gene that conveys higher risk for breast cancer with this information?)

Yes No Don't Know

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.

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		
		1	2	3	4	5	
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.
l.	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.
o.	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. A medical test may soon be available that allows some women to learn their genetic risk for developing a form of breast and ovarian cancer that runs in families. Would you consider taking this genetic test?
(Please check one response).

B15.

- (1)._____ I will definitely take the test immediately when it becomes available.
 (2)._____ I will definitely take the test, but I am not sure if immediately.
 (3)._____ I will probably take the test immediately when it becomes available.
 (4)._____ I will probably take the test, but not immediately.
 (5)._____ I am undecided whether I will take the test
 (6)._____ I will probably not take the test.
 (7)._____ I will definitely not take the test.

2. On the following scale, indicate how distressing it is for you to know that you may be at increased risk for breast cancer because of your family history?

B66.

Not At All Distressing					Very Distressing
1	2	3	4	5	

3. How distressing it is to be given the opportunity to be tested for the BRCA-1 gene, the altered gene associated with increased risk for breast cancer?

B67.

Not At All Distressing					Very Distressing
1	2	3	4	5	

4. How distressed do you expect to be when you actually get tested for the BRCA-1 gene (before you receive results)?

B68.

Not At All Distressed					Very Distressed
1	2	3	4	5	

5. How distressed would you be if you took the test and found that you **had** the BRCA-1 gene?

B69.

Not At All Distressed					Very 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? **B70.**

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.**

Not At All					Very Much So
1	2	3	4	5	

		<i>Not At All</i>			<i>All The Time</i>		
		1	2	3	4	5	
8.	How often do you worry about developing breast cancer?						B27.
9.	To what extent do these worries interfere with your every day life?						B28.
10.	How often do you worry about having the altered gene carrying risk for breast cancer ?						B29.
11.	To what extent do these worries you have about having this altered gene interfere with your every day life?						B30.

12. When was the last time you had a mammography? **B32.**

_____Month _____Year ⁽⁻⁸⁾ This question does not apply because of surgery.

13. How many times have you conducted a breast self-examinations (BSE) in the past six months? **B33.**

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

14. How confident are you that you will perform breast self examination (BSE) ---

14a. --as **frequently** as needed? (-8) Does Not Apply Because of Surgery **B34a.**

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

14b. --as **carefully and competently** as needed? **B34b.**

(-8) Does Not Apply Because of Surgery

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

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

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

		<i>Have been affected by being at risk for breast cancer</i>					<i>Would be affected by the results of genetic testing</i>					
		1	2	3	4	5	1	2	3	4	5	
15.	Decisions about having children											B35a B35b
16.	Decisions about form of birth control											B36a B36b
17.	Decisions about which steps to take to prevent the occurrence of breast cancer											B37a B37b
18.	Decisions about work and career											B38a B38b
19.	Decisions about savings and financial planning											B39a B39b
20.	Decisions about plans for the future											B40a B40b

21. Answer the following question only if you have (biological) daughters.

Does Not Apply
(Skip to Question 22)

B41.

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

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.

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

B46.

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						Very Much
1	2	3	4	5	6	7

B48a.

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

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

B48b.

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

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

B48c.

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
1	2	3	4	5	6	7

B48d.

RELATIONSHIPS SECTION

1. Is there anyone in your life with whom you can share your most private feelings without holding back? C21.
(1) Yes (5) No
2. If married, can you share your most private feelings with your husband without holding back? C21a.
(1) Yes (5) No
3. If married, is there anyone besides your husband with whom you can share your most private feelings without holding back? C21b.
(1) Yes (5) No
-

LIFE EVENTS SECTION

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

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

E-a.

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.

		<i>Always Agree</i>	<i>Almost Always Agree</i>	<i>Occasionally Disagree</i>	<i>Frequently Disagree</i>	<i>Almost Always Disagree</i>	<i>Always Disagree</i>	
1.	Religious matters	6	5	4	3	2	1	H3.
2.	Demonstration of affection	6	5	4	3	2	1	H4.
3.	Sex relations	6	5	4	3	2	1	H6.
4.	Conventionality (correct or proper behavior)	6	5	4	3	2	1	H7.
5.	Making major decisions	6	5	4	3	2	1	H12.
6.	Career decisions	6	5	4	3	2	1	H15.

		<i>All of the time</i>	<i>Most of the time</i>	<i>More often than most</i>	<i>Occasionally</i>	<i>Rarely</i>	<i>Never</i>	
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.

		<i>All of Them</i>	<i>Most of Them</i>	<i>Some of Them</i>	<i>Very few of Them</i>	<i>None of Them</i>
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?

		<i>Never</i>	<i>Less than once a month</i>	<i>About twice a month</i>	<i>About twice a week</i>	<i>Once a day</i>	<i>More Often</i>
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 At All Positive									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 At All Negative									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.

		<i>Never</i> <i>Very Often</i>					
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	H35c.
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, family or group sessions to become informed about your risk for breast cancer and what can be done? **H36.**

1
5
 Yes No

19. How much contact has your husband/partner had with medical personnel concerning your risk for breast cancer. **H37.**

Very Little or None A lot
 1 2 3 4 5 6 7

20. Do you feel your husband/partner is adequately informed concerning your risk for breast cancer and what can be done about it? **H38.**

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

21. To what extent are you satisfied with your husband/partner's involvement in your health care? **H39.**

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

MOOD SECTION

1. Have you **ever in your lifetime** had two weeks or more when nearly every day you felt sad, blue, or depressed or in which you lost all interest in things like work or hobbies or things you usually liked to do for fun? I14
- 1 5
 Yes No (Skip to Question 2)
- 1a. If there was such a two-week period, did your work or relationships suffer? I14a.
- 1 5
 Yes No
- 1b. If there was such a two-week period, did you get counseling or psychotherapy? I14b.
- 1 5
 Yes No
- 1c. If there was such a two-week period, did you get medication for this condition? I14c.
- 1 5
 Yes No
-
2. In the **past 6 months**, have you had two weeks or more when nearly every day you felt sad, blue, or depressed or in which you lost all interest in things like work or hobbies or things you usually liked to do for fun? I12.
- 1 5
 Yes No (Skip to Question 3)
- 2a. If there was such a two-week period in **the past 6 months**, did your work or relationships suffer? I12a.
- 1 5
 Yes No
- 2b. If there was such a two-week period in **the past 6 months**, did you get counseling or psychotherapy? I12b.
- 1 5
 Yes No
- 2c. If there was such a two-week period in **the past 6 months**, did you get medication for this condition? I12c.
- 1 5
 Yes No
-
3. Are you **currently** receiving counseling, psychotherapy or medication for depression or emotional problems? I13.
- 1 5
 Yes 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 **Past Three Months.***

		<u>Not at all</u>	<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	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 energy--slowed 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 positively by your risk of breast cancer.

		<i>Not At All</i>	<i>A Very Small Degree</i>	<i>A Small Degree</i>	<i>A Moderate Degree</i>	<i>A Great Degree</i>	<i>A Very Great Degree</i>	
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	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>I haven't been doing this at all 1</i>	<i>I've been doing this a little bit 2</i>	<i>I've been doing this some 3</i>	<i>I've been doing this a lot 4</i>	
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 the 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.
l.	I've been trying to come up with a strategy about what to do.	1	2	3	4	L7l.
m.	I've been getting comfort and understanding from someone.	1	2	3	4	L7m.

		<i>I haven't been doing this at all</i> 1	<i>I've been doing this a little bit</i> 2	<i>I've been doing this some</i> 3	<i>I've been doing this a lot</i> 4	
n.	I've been giving up the attempt to cope.	1	2	3	4	L7n.
o.	I've been accepting the possibility that I might have the gene.	1	2	3	4	L7o.
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 might have the 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.

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

Not married or living with a partner

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

L8.

		<i>I haven't been doing this at all</i> 1	<i>I've been doing this a little bit</i> 2	<i>I've been doing this some</i> 3	<i>I've been doing this a lot</i> 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: Catholic (1) Protestant (4) **A3.**
Jewish (2) Buddhist (5)
Muslim (3) Other (6)
None (7)

- 1a. How often do you attend religious services? **A3a.**
(1) (5)
 Less Often Than Once a Month A Few Times A Month or More

- 1b. How important are religious and spiritual beliefs in your life? **A3b.**
Not at All Very Important
1 2 3 4 5

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



WOMEN'S HEALTH STUDY
Spouse/Partner Questionnaire

Today's Date _____

U-ID _____

SPOP

BACKGROUND DATA SECTION

1. Date of Birth _____ Month _____ Day _____ Year **A1.**
2. Ethnic Background: White 1 Black 4 **A2.**
Hispanic 2 Asian 5
Native American 3 Other 6
3. Religion: Catholic 1 Protestant 4 **A3.**
Jewish 2 Buddhist 5
Muslim 3 Other 6
None 7
- 3a. How often do you attend religious services? **A3a.**
 1 Less Than Once a Month 5 A Few Times A Month or More
- 3b. How important are religious and spiritual beliefs in your life? **A3b.**
Not at All Very Important
1 2 3 4 5
4. Are you currently working for pay outside the home? Yes 1 No 5 **A7.**
5. If yes, about how many hours per week are you working for pay? **A8.**
Less than 10 10-20 21-30 31-40 41 or more

(1) (2) (3) (4) (5)
6. What is the highest level of education you have completed? (**Check one**) **A9.**
1 Less than 9th grade 5 Completed college
2 Dropped out of high school 6 Some graduate or professional training
3 Completed high school 7 Completed graduate or professional training
4 Some college
- The following two questions are optional, but we hope that you will provide this information. Please check the appropriate box. (Check one)**
7. What is your household's total income? (**Check one**) **A10.**
(1) Less than \$10,000 (4) \$30,000 to \$39,999 (7) \$60,000 to \$69,999
(2) \$10,000 to \$19,999 (5) \$40,000 to \$49,999 (8) Greater than \$69,999
(3) \$20,000 to \$29,999 (6) \$50,000 to \$59,999
8. How many people (adults and children) does this income support? _____ **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.

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		
		1	2	3	4	5	
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.
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.
l.	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.
o.	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.

		<i>Not At All</i>			<i>All The Time</i>		
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	B30.
5.	How often do you worry about developing cancer yourself?	1	2	3	4	5	B31.

6. How likely do you think your wife/partner is to develop breast cancer 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 **at some point in her lifetime?** B10.

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

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? B49.

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

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

22. 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 7 Very Much

1

23. Do you feel you are adequately informed about the benefits and drawbacks of genetic testing for risk of breast cancer? **B44.**

Not at All 2 3 4 5 6 7 Very Much

1

24. Do you feel you are adequately informed about what your wife/partner could do personally to reduce her risk of breast cancer if she had the altered BRCA1 gene? **B45.**

Not at All 2 3 4 5 6 7 Very Much

1

25. Do you feel you are adequately informed about the benefits and drawbacks of options available to women who have the altered BRCA1 gene? **B46.**

Not at All 2 3 4 5 6 7 Very Much

1

26. Do you feel you are adequately informed about what it would mean for your children if your wife/partner had the altered BRCA1 gene? **Check here if you do not have children.** **B47.**

Not at All 2 3 4 5 6 7 Very Much

1

27. How confident are you that your wife/partner:

27a. Will make the best decision about whether to be tested for BRCA1, the altered gene associated with risk of breast cancer? **B48a.**

Not at All 2 3 4 5 6 7 Very Much

1

27b. Would cope effectively with the finding that she had the altered BRCA1 gene? **B48b.**

Not at All 2 3 4 5 6 7 Very Much

1

27c. Would make the best decision concerning her options if she were found to have the altered BRCA1 gene? **B48c.**

Not at All 2 3 4 5 6 7 Very Much

1

27d. 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.**

Not at All 2 3 4 5 6 7 Very Much

1

28. 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.

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		<i>I Don't Know</i>	
		1	2	3	4	5	9	
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	B20b.
c.	Mammography can detect lumps that cannot be felt by a woman or by her doctor.	1	2	3	4	5	9	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.
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	B20p.
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.
l.	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 **did not** 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?

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		
		1	2	3	4	5	
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 **had** the altered version of the BRCA1 gene for breast cancer, what would you expect your reactions to be?

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		
		1	2	3	4	5	
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	B19c.
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.	1	2	3	4	5	B19k.

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

		<i>Not at All</i>					<i>Very Often</i>
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	H35b.
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	H35c.
d.	To what extent do you change your activities to look after your wife/partner?	1	2	3	4	5	H35d.

32. 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 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? C21.
(1) Yes (5) No
2. Can you share your most private feelings with your wife/partner without holding back? C21a.
(1) Yes (5) No
3. Is there anyone besides your wife/partner with whom you can share your most private feelings without holding back? C21b.
(1) Yes (5) No
4. Have any of the events listed below happened to you in the past six months? D1 (a-m)
(Check All That Apply)
- | | |
|---|---|
| a. <input type="checkbox"/> You retired or were fired or laid off from work. | g. <input type="checkbox"/> A close family member was seriously ill or injured. |
| b. <input type="checkbox"/> You were unemployed and looking for work. | h. <input type="checkbox"/> You had a marital separation or divorce. |
| c. <input type="checkbox"/> Your spouse retired or was fired or laid off from work. | i. <input type="checkbox"/> You had serious troubles with relatives or close friends. |
| d. <input type="checkbox"/> Your spouse was unemployed and looking for work. | j. <input type="checkbox"/> Your spouse had troubles with relatives or close friends. |
| e. <input type="checkbox"/> You had problems with the police or court. | k. <input type="checkbox"/> A close family member died. |
| f. <input type="checkbox"/> You got into serious financial difficulties. | l. <input type="checkbox"/> A close friend or relative died. |
| | m. <input type="checkbox"/> 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.**

		<i>Always Agree</i>	<i>Almost Always Agree</i>	<i>Occasionally Disagree</i>	<i>Frequently Disagree</i>	<i>Almost Always Disagree</i>	<i>Always Disagree</i>	
1.	Handling family finances	1	2	3	4	5	6	H1.
2.	Matters of recreation	1	2	3	4	5	6	H2.
3.	Religious matters	1	2	3	4	5	6	H3.
4.	Demonstration of affection	1	2	3	4	5	6	H4.
5.	Friends	1	2	3	4	5	6	H5.
6.	Sex relations	1	2	3	4	5	6	H6.
7.	Conventionality (correct or proper behavior)	1	2	3	4	5	6	H7.
8.	Philosophy of life	1	2	3	4	5	6	H8.
9.	Ways of dealing with parents or in-laws	1	2	3	4	5	6	H9.
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.	Making major decisions	1	2	3	4	5	6	H12.
13.	Household tasks	1	2	3	4	5	6	H13.
14.	Leisure time interests and activities	1	2	3	4	5	6	H14.
15.	Career decisions	1	2	3	4	5	6	H15.

		<i>All of the Time</i>	<i>Most of the Time</i>	<i>More Often than Most</i>	<i>Occasionally</i>	<i>Rarely</i>	<i>Never</i>
16.	How often do you discuss or have you considered divorce, separation, or terminating your relationship?	1	2	3	4	5	6
17.	How often do you or your wife/partner leave the house after a fight?	1	2	3	4	5	6
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
19.	Do you confide in your wife/partner?	1	2	3	4	5	6
20.	Do you ever regret that you married (or lived together)?	1	2	3	4	5	6
21.	How often do you and your wife/partner quarrel?	1	2	3	4	5	6
22.	How often do you and your wife/partner "get on each other's nerves?"	1	2	3	4	5	6

H16.

H17.

H18.

H19.

H20.

H21.

H22.

		<i>Every Day</i>	<i>Almost Every Day</i>	<i>Occasionally</i>	<i>Rarely</i>	<i>Never</i>
23.	Do you kiss your wife/partner?	1	2	3	4	5

H23.

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

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 yes or no).**

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

H29.

30. Not showing love. (1) 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	Happy	Very Happy	Extremely Happy	Perfect
1	2	3	4	5	6	7

32. Please check one 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 I can't do much more than I am doing now to help it succeed.

(5).___ It would be nice if it succeeded, but I refuse to do any more than I am doing now to keep the relationship going.

(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									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 Negative									Extremely 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).

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

YOUR HEALTH AND MOOD SECTION

1. In general, would you say your health is: I1.
- (1) Excellent (2) Very Good (3) Good (4) Fair (5) Poor
2. Have you **ever in your life** had two weeks or more when nearly every day you felt sad, blue, or depressed or in which you lost all interest in things like work or hobbies or things you usually liked to do for fun? I14.
- (1) Yes (5) No (Skip to Question 3)
- 2a. If there was such a two-week period, did your work or relationships suffer? I14a.
- (1) Yes (5) No
- 2b. If there was such a two-week period, did you get counseling or psychotherapy? I14b.
- (1) Yes (5) No
- 2c. If there was such a two-week period, did you get medication for this condition? I14c.
- (1) Yes (5) No
3. In the **past 6 months**, have you had two weeks or more when nearly every day you felt sad, blue, or depressed or in which you lost all interest in things like work or hobbies or things you usually liked to do for fun? I12.
- (1) Yes (5) No (Skip to Question 4)
- 3a. If there was such a two-week period (**in the past 6 months**), did your work or relationships suffer? I12a.
- (1) Yes (5) No
- 3b. If there was such a two-week period (**in the past 6 months**), did you get counseling or psychotherapy? I12b.
- (1) Yes (5) No
- 3c. If there was such a two-week period, (**in the past 6 months**) did you get medication for this problem? I12c.
- (1) Yes (5) No
4. Are you **currently** receiving counseling, psychotherapy, or medication for depression or emotional problems? I13.
- (1) Yes (5) No

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.*

		<i>1</i> <i>Not at all</i>	<i>2</i> <i>A little</i>	<i>3</i> <i>Quite a bit</i>	<i>4</i> <i>Extremely</i>	
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 energy--slowed 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. 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.

		<i>YES</i>	<i>NO</i>	
a.	I would ask the dentist exactly what s/he was going to do.	1	5	L1_1
b.	I would take a tranquilizer or have a drink before going.	1	5	L1_2
c.	I would try to think about pleasant memories.	1	5	L1_3
d.	I would want the dentist to tell me when I would feel pain.	1	5	L1_4
e.	I would try to sleep.	1	5	L1_5
f.	I would watch all the dentist's movements and listen for the sound of the drill.	1	5	L1_6
g.	I would watch the flow of water from my mouth to see if it contained blood.	1	5	L1_7
h.	I would do mental puzzles in my mind.	1	5	L1_8

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?

		<i>YES</i>	<i>NO</i>	
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>I haven't been doing this at all 1</i>	<i>I've been doing this a little bit 2</i>	<i>I've been doing this some 3</i>	<i>I've been doing this a lot 4</i>	
a.	I've been turning to work or other activities to take my mind off things.	1	2	3	4	L7_a.
b.	I've been concentrating my efforts on doing something about her situation.	1	2	3	4	L7_b.
c.	I've been saying to myself "this isn't possible."	1	2	3	4	L7_c.
d.	I've been using alcohol or other drugs to make myself feel better.	1	2	3	4	L7_d.
e.	I've been getting emotional support from others.	1	2	3	4	L7_e.
f.	I've been giving up trying to deal with it.	1	2	3	4	L7_f.
g.	I've been taking action to try to make the situation better.	1	2	3	4	L7_g.
h.	I've been refusing to believe that it is possible she has the gene.	1	2	3	4	L7_h.
i.	I've been saying things to let my unpleasant feelings escape.	1	2	3	4	L7_i.
j.	I've been using alcohol or other drugs to help me get through it.	1	2	3	4	L7_j.
k.	I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4	L7_k.
l.	I've been trying to come up with a strategy for what to do.	1	2	3	4	L7_l.
m.	I've been getting comfort and understanding from someone.	1	2	3	4	L7_m.

		<i>I haven't been doing this at all</i> 1	<i>I've been doing this a little bit</i> 2	<i>I've been doing this some</i> 3	<i>I've been doing this a lot</i> 4	
n.	I've been giving up the attempt to cope.	1	2	3	4	L7_n.
o.	I've been accepting the possibility that she might have the gene.	1	2	3	4	L7_o.
p.	I've been expressing my negative feelings.	1	2	3	4	L7_p.
q.	I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4	L7_q.
r.	I've been learning to live with the possibility she might have the gene.	1	2	3	4	L7_r.
s.	I've been thinking hard about what steps to take.	1	2	3	4	L7_s.
t.	I've been praying or meditating.	1	2	3	4	L7_t.
u.	I've been making fun of the situation.	1	2	3	4	L7_u.
v.	I've been giving pep talks and encouraging my wife/partner.	1	2	3	4	L7_v.
w.	I've been denying or hiding my anger around my wife/partner.	1	2	3	4	L7_w.
x.	I've been denying or hiding my own worries around my wife/partner.	1	2	3	4	L7_x.
y.	I've been trying to give my wife/partner opportunities to talk about her worries.	1	2	3	4	L7_y.
z.	I've been trying to find out what my wife/partner is feeling.	1	2	3	4	L7_z.
aa.	I've been avoiding talking about my own problems around my wife/partner.	1	2	3	4	L7_aa.
bb.	I've acted more positive around my wife/partner than I feel.	1	2	3	4	L7_bb.

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 **no change** 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 **very small degree** 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 **small degree** 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 **very great degree** as a result of my wife/partner possibly having an altered gene associated with greater risk for breast cancer.

		<i>No Change</i>	<i>Very Small Degree</i>	<i>Small Degree</i>	<i>Moderate Degree</i>	<i>Great Degree</i>	<i>Very Great Degree</i>	
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.



WOMEN'S HEALTH STUDY

Spouse/Partner Questionnaire

Today's Date _____

A-ID _____

SPOP

BACKGROUND DATA SECTION

1. Date of Birth _____ Month _____ Day _____ Year **A1.**
2. Ethnic Background: White 1 Black 4 **A2.**
 Hispanic 2 Asian 5
 Native American 3 Other 6
3. Religion: Catholic 1 Protestant 4 **A3.**
 Jewish 2 Buddhist 5
 Muslim 3 Other 6
 None 7
- 3a. How often do you attend religious services? **A3a.**
 1 Less Than Once a Month 5 A Few Times A Month or More
- 3b. How important are religious and spiritual beliefs in your life? **A3b.**
 Not at All 1 2 3 4 5 Very Important
4. Are you currently working for pay outside the home? Yes 1 No 5 **A7.**
5. If **yes**, about how many hours per week are you working for pay? **A8.**
Less than 10 10-20 21-30 31-40 41 or more

(1) (2) (3) (4) (5)
6. What is the highest level of education you have completed? **(Check one)** **A9.**
1 Less than 9th grade 5 Completed college
2 Dropped out of high school 6 Some graduate or professional training
3 Completed high school 7 Completed graduate or professional training
4 Some college

The following two questions are optional, but we hope that you will provide this information. Please check the appropriate box. (Check one)

7. What is your household's total income? **(Check one)** **A10.**
(1) Less than \$10,000 (4) \$30,000 to \$39,999 (7) \$60,000 to \$69,999
(2) \$10,000 to \$19,999 (5) \$40,000 to \$49,999 (8) Greater than \$69,999
(3) \$20,000 to \$29,999 (6) \$50,000 to \$59,999
8. How many people (adults and children) does this income support? _____ **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.

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

		<i>Not At All</i>			<i>All The Time</i>		
		1	2	3	4	5	
1.	How often do you worry about your wife/partner again 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	B30.
5.	How often do you worry about developing cancer yourself?	1	2	3	4	5	B31.

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?** B10.

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

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? B49.

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

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

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 Very Much
 1 2 3 4 5 6 7

22b. Do you feel you are adequately informed about your wife/partner's risk for developing breast cancer **again**? **B43b.**

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

22c. Do you feel you are adequately informed about the benefits and drawbacks of genetic testing for risk of breast cancer? **B44.**

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

22d. Do you feel you are adequately informed about what your wife/partner could do personally to reduce her risk of breast cancer if she had the altered BRCA1 gene? **B45.**

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

22e. Do you feel you are adequately informed about the benefits and drawbacks of options available to women who have the altered BRCA1 gene? **B46.**

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

22f. Do you feel you are adequately informed about what it would mean for your children if your wife/partner had the altered BRCA1 gene? **B47.**
 Check here if you do not have children.

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

C-22f.

23. How confident are you that your wife/partner:

23a. Will make the best decision about whether to be tested for BRCA1, the altered gene associated with risk of breast cancer? **B48a.**

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

23b. Would cope effectively with the finding that she had the altered BRCA1 gene? **B48b.**

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

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

23c. Would make the best decision concerning her options if she were found to have the altered BRCA1 gene? B48c.

Not at All 2 3 4 5 6 7 Very Much

23d. 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.

Not at All 2 3 4 5 6 7 Very Much

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.

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		<i>I Don't Know</i>	
		1	2	3	4	5	9	
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	B20b.
c.	Mammography can detect lumps that cannot be felt by a woman or by her doctor.	1	2	3	4	5	9	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.
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	B20p.
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.

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		<i>I Don't Know</i>
l.	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 breakthroughs are going to make breast cancer much less of a threat to women's health.	1	2	3	4	5	9

B20r.

B20s.

25. If your wife/partner were to take the test and find that she **did not** 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?

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		
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.

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

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		
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	B19c.
d.	I would feel guilty.	1	2	3	4	5	B19d.
e.	I would feel depressed.	1	2	3	4	5	B19e.

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		
		1	2	3	4	5	
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:

		<i>Not at All</i>			<i>Very Often</i>		
		1	2	3	4	5	
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	H35b.
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	H35c.
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.**

<i>Not at All</i>						<i>Very Much So</i>
1	2	3	4	5	6	7

b. Getting preventive surgery. **B64b.**

<i>Not at All</i>						<i>Very Much So</i>
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 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? **C21.**
 (1) Yes (5) No
2. Can you share your most private feelings with your wife/partner without holding back? **C21a.**
 (1) Yes (5) No
3. Is there anyone besides your wife/partner with whom you can share your most private feelings without holding back? **C21b.**
 (1) Yes (5) No
4. Have any of the events listed below happened to you in the past six months? **D1 (a-m)**
(Check All That Apply)
- | | |
|---|---|
| <p>a. <input type="checkbox"/> You retired or were fired or laid off from work.</p> <p>b. <input type="checkbox"/> You were unemployed and looking for work.</p> <p>c. <input type="checkbox"/> Your spouse retired or was fired or laid off from work.</p> <p>d. <input type="checkbox"/> Your spouse was unemployed and looking for work.</p> <p>e. <input type="checkbox"/> You had problems with the police or court.</p> <p>f. <input type="checkbox"/> You got into serious financial difficulties.</p> | <p>g. <input type="checkbox"/> A close family member was seriously ill or injured.</p> <p>h. <input type="checkbox"/> You had a marital separation or divorce.</p> <p>i. <input type="checkbox"/> You had serious troubles with relatives or close friends.</p> <p>j. <input type="checkbox"/> Your spouse had troubles with relatives or close friends.</p> <p>k. <input type="checkbox"/> A close family member died.</p> <p>l. <input type="checkbox"/> A close friend or relative died.</p> <p>m. <input type="checkbox"/> You were seriously ill or injured.</p> |
|---|---|

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**.

		<i>Always Agree</i>	<i>Almost Always Agree</i>	<i>Occasionally Disagree</i>	<i>Frequently Disagree</i>	<i>Almost Always Disagree</i>	<i>Always Disagree</i>	
1.	Handling family finances	1	2	3	4	5	6	H1.
2.	Matters of recreation	1	2	3	4	5	6	H2.
3.	Religious matters	1	2	3	4	5	6	H3.
4.	Demonstration of affection	1	2	3	4	5	6	H4.
5.	Friends	1	2	3	4	5	6	H5.
6.	Sex relations	1	2	3	4	5	6	H6.
7.	Conventionality (correct or proper behavior)	1	2	3	4	5	6	H7.
8.	Philosophy of life	1	2	3	4	5	6	H8.
9.	Ways of dealing with parents or in-laws	1	2	3	4	5	6	H9.
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.	Making major decisions	1	2	3	4	5	6	H12.
13.	Household tasks	1	2	3	4	5	6	H13.
14.	Leisure time interests and activities	1	2	3	4	5	6	H14.
15.	Career decisions	1	2	3	4	5	6	H15.

		<i>All of the Time</i>	<i>Most of the Time</i>	<i>More Often than Most</i>	<i>Occasionally</i>	<i>Rarely</i>	<i>Never</i>
16.	How often do you discuss or have you considered divorce, separation, or terminating your relationship?	1	2	3	4	5	6
17.	How often do you or your wife/partner leave the house after a fight?	1	2	3	4	5	6
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
19.	Do you confide in your wife/partner?	1	2	3	4	5	6
20.	Do you ever regret that you married (or lived together)?	1	2	3	4	5	6
21.	How often do you and your wife/partner quarrel?	1	2	3	4	5	6
22.	How often do you and your wife/partner "get on each other's nerves?"	1	2	3	4	5	6

H16.

H17.

H18.

H19.

H20.

H21.

H22.

		<i>Every Day</i>	<i>Almost Every Day</i>	<i>Occasionally</i>	<i>Rarely</i>	<i>Never</i>
23.	Do you kiss your wife/partner?	1	2	3	4	5

H23.

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

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	H25.
26.	Laugh together	1	2	3	4	5	6	H26.
27.	Calmly discuss something	1	2	3	4	5	6	H27.
28.	Work together on a project	1	2	3	4	5	6	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) Yes (5) No H29.
30. Not showing love. (1) 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	Happy	Very Happy	Extremely Happy	Perfect
1	2	3	4	5	6	7

32. Please check one 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 I can't do much more than I am doing now to help it succeed.
- (5).___ It would be nice if it succeeded, but I refuse to do any more than I am doing now to keep the relationship going.
- (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					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 Negative					Extremely 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).

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		
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	M3.
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	M7.
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	M9.
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: I1.
(1) Excellent (2) Very Good (3) Good (4) Fair (5) Poor
2. Have you **ever in your life** had two weeks or more when nearly every day you felt sad, blue, or depressed or in which you lost all interest in things like work or hobbies or things you usually liked to do for fun? I14.
(1) Yes (5) No (Skip to Question 3)
- 2a. If there was such a two-week period, did your work or relationships suffer? I14a.
(1) Yes (5) No
- 2b. If there was such a two-week period, did you get counseling or psychotherapy? I14b.
(1) Yes (5) No
- 2c. If there was such a two-week period, did you get medication for this condition? I14c.
(1) Yes (5) No
3. In the **past 6 months**, have you had two weeks or more when nearly every day you felt sad, blue, or depressed or in which you lost all interest in things like work or hobbies or things you usually liked to do for fun? I12.
(1) Yes (5) No (Skip to Question 4)
- 3a. If there was such a two-week period (**in the past 6 months**), did your work or relationships suffer? I12a.
(1) Yes (5) No
- 3b. If there was such a two-week period (**in the past 6 months**), did you get counseling or psychotherapy? I12b.
(1) Yes (5) No
- 3c. If there was such a two-week period, (**in the past 6 months**) did you get medication for this problem? I12c.
(1) Yes (5) No
4. Are you **currently** receiving counseling, psychotherapy, or medication for depression or emotional problems? I13.
(1) Yes (5) No

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.*

		<i>1</i> <i>Not at all</i>	<i>2</i> <i>A little</i>	<i>3</i> <i>Quite a bit</i>	<i>4</i> <i>Extremely</i>	
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 energy--slowed 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. 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.

		<i>YES</i>	<i>NO</i>	
a.	I would ask the dentist exactly what s/he was going to do.	1	5	L1_1
b.	I would take a tranquilizer or have a drink before going.	1	5	L1_2
c.	I would try to think about pleasant memories.	1	5	L1_3
d.	I would want the dentist to tell me when I would feel pain.	1	5	L1_4
e.	I would try to sleep.	1	5	L1_5
f.	I would watch all the dentist's movements and listen for the sound of the drill.	1	5	L1_6
g.	I would watch the flow of water from my mouth to see if it contained blood.	1	5	L1_7
h.	I would do mental puzzles in my mind.	1	5	L1_8

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?

		<i>YES</i>	<i>NO</i>	
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.

		<i>YES</i>	<i>NO</i>	
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.

		<i>YES</i>	<i>NO</i>	
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>I haven't been doing this at all</i> 1	<i>I've been doing this a little bit</i> 2	<i>I've been doing this some</i> 3	<i>I've been doing this a lot</i> 4	
a.	I've been turning to work or other activities to take my mind off things.	1	2	3	4	L7_a.
b.	I've been concentrating my efforts on doing something about her situation.	1	2	3	4	L7_b.
c.	I've been saying to myself "this isn't possible."	1	2	3	4	L7_c.
d.	I've been using alcohol or other drugs to make myself feel better.	1	2	3	4	L7_d.
e.	I've been getting emotional support from others.	1	2	3	4	L7_e.
f.	I've been giving up trying to deal with it.	1	2	3	4	L7_f.
g.	I've been taking action to try to make the situation better.	1	2	3	4	L7_g.
h.	I've been refusing to believe that it is possible she has the gene.	1	2	3	4	L7_h.
i.	I've been saying things to let my unpleasant feelings escape.	1	2	3	4	L7_i.
j.	I've been using alcohol or other drugs to help me get through it.	1	2	3	4	L7_j.
k.	I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4	L7_k.
l.	I've been trying to come up with a strategy for what to do.	1	2	3	4	L7_l.

		<i>I haven't been doing this at all</i> 1	<i>I've been doing this a little bit</i> 2	<i>I've been doing this some</i> 3	<i>I've been doing this a lot</i> 4	
m.	I've been getting comfort and understanding from someone.	1	2	3	4	L7_m.
n.	I've been giving up the attempt to cope.	1	2	3	4	L7_n.
o.	I've been accepting the possibility that she might have the gene.	1	2	3	4	L7_o.
p.	I've been expressing my negative feelings.	1	2	3	4	L7_p.
q.	I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4	L7_q.
r.	I've been learning to live with the possibility she might have the gene.	1	2	3	4	L7_r.
s.	I've been thinking hard about what steps to take.	1	2	3	4	L7_s.
t.	I've been praying or meditating.	1	2	3	4	L7_t.
u.	I've been making fun of the situation.	1	2	3	4	L7_u.
v.	I've been giving pep talks and encouraging my wife/partner.	1	2	3	4	L7_v.
w.	I've been denying or hiding my anger around my wife/partner.	1	2	3	4	L7_w.
x.	I've been denying or hiding my own worries around my wife/partner.	1	2	3	4	L7_x.
y.	I've been trying to give my wife/partner opportunities to talk about her worries.	1	2	3	4	L7_y.
z.	I've been trying to find out what my wife/partner is feeling.	1	2	3	4	L7_z.
aa.	I've been avoiding talking about my own problems around my wife/partner.	1	2	3	4	L7_aa.
bb.	I've acted more positive around my wife/partner than I feel.	1	2	3	4	L7_bb.

The following questions concern coping with your wife/partner's diagnosis and treatment for cancer:

6. **At your worst**, how distressed did you feel about your wife/partner's diagnosis and treatment of cancer? **L8.**
- | | | | | | | |
|------------|---|---|---|---|---|-----------|
| Not at All | | | | | | Very Much |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
-
7. During that time, did you ever have two weeks or more when nearly every day you felt sad, blue, or depressed or in which you lost all interest in things like work or hobbies or things you usually like to do for fun? **L9.**
- (1) Yes (5) No (Skip to Question 8)
- a. If there was such a two-week period, did your work or relationships suffer? **L9a.**
- (1) Yes (5) No
- b. If there was such a two-week period, did you get counseling or psychotherapy? **L9b.**
- (1) Yes (5) No
- c. If there was such a two-week period, did you get medication for this problem? **L9c.**
- (1) Yes (5) No
-
8. 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 being diagnosed and treated for breast cancer. Please use the following scale:
- 1 = I experienced **no** change as a result of my wife/partner's being diagnosed and treated for cancer.
 - 2 = I experienced this change to a **very small degree** as a result of my wife/partner's being diagnosed and treated for cancer.
 - 3 = I experienced this change to a **small degree** as a result of my wife/partner's being diagnosed and treated for cancer.
 - 4 = I experienced this change to a **moderate degree** as a result of my wife/partner's being diagnosed and treated for cancer.
 - 5 = I experienced this change to a **great degree** as a result of my wife/partner's being diagnosed and treated for cancer.
 - 6 = I experienced this change to a **very great degree** as a result of my wife/partner's being diagnosed and treated for cancer.
- Does not apply because I was not with my wife/partner when she was being treated for breast cancer. **L6.**

		<i>No Change</i>	<i>Very Small Degree</i>	<i>Small Degree</i>	<i>Moderate Degree</i>	<i>Great Degree</i>	<i>Very Great Degree</i>	
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.

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.

		<i>Never</i>					<i>Very Often</i>	
		1	2	3	4	5		
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	L10l.	

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



WOMEN'S HEALTH STUDY

Pre-Results Questionnaire

TODAY'S DATE _____

ID _____

PRE-RESULTS ASSESSMENT - U

You may notice that some of these questions were asked in previous questionnaires, but many of the questions are new. 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) Yes (5) No

2. Has any member of your family met with someone to have genetic counseling? **B25.**
(1) Yes (5) No

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

Decreased Very Much 1	Decreased Slightly 2	No Change 3	Increased Slightly 4	Increased Very Much 5
-------------------------------------	------------------------------------	---------------------------	------------------------------------	-------------------------------------

4. At this time, what is your decision regarding receiving your genetic results? **B112.**
(1) I will probably or definitely receive my results now, as soon as they are offered.
(Skip to Question 4)

(3) I do not intend to receive my results now, but may do so later. (Skip to Question 5)

(5) I do not intend to receive my results now or in the future. (Skip to Question 6)

5. If you will probably or definitely obtain your results ***now***, as soon as they are being offered to you, what are your reasons for doing so? **B113.**
(Please check all that apply and then circle the number of the statement which indicates your most important reason for receiving your results *now*).

(1) I just want to know whether I have the gene. I am happier knowing.

(2) In order to decide whether to get prophylactic surgery.

(3) To assist me in other medical decisions.

(4) To make decisions about family planning.

(5) To make decisions about financial planning and insurance.

(6) To make lifestyle and other non-medical decisions.

(7) To find out the risk that may be transmitted to my children.

(8) Family members want me to get testing.

(9) I want to help other family members by providing them with my results.

(10) Other (please describe) _____

6. If you do ***not*** intend to obtain your results ***now***, but may do so ***later***, please indicate your reasons. B114.

(Please check all that apply and then circle the number of the statement which indicates your most important reason for delaying receiving your results).

- (1) I am happier not knowing.
- (2) There are no decisions I need to make at this time for which knowledge of my results would be useful.
- (3) It would be too upsetting to learn that I have a mutation associated with increased risk of cancer.
- (4) Knowing that I have a mutation would interfere with my life as it is now.
- (5) There would not be much I could now do to reduce my risk of cancer if I found out I had a mutation.
- (6) I am too worried about the effects of knowing my results on women in my family.
- (7) Family members do not want me to get testing.
- (8) Family members want me to get testing, but I am not ready to do so.
- (9) I want to wait until there is less risk to insurance coverage.
- (10) I want to wait until there is less risk to employment.
- (11) I am either too young or too old to benefit from knowing if I have a mutation.
- (12) I want to wait until more is known about breast/ovarian cancer genes and what can be done to reduce a women's risk of cancer.
- (13) I simply am not ready to make up my mind at this time.
- (14) Other (please describe) _____

7. If you do ***not*** intend to obtain your results ***now or in the future***, please indicate your reasons. B115.

(Please check all that apply and then circle the number of the statement which indicates your most important reason for not receiving your results).

- (1) I am happier not knowing.
- (2) There are no decisions I need to make for which knowledge of my results would be useful.
- (3) It would be too upsetting to learn that I have a mutation associated with increased risk of cancer.
- (4) Knowing that I have a mutation would interfere with my life.
- (5) There would not be much I could do to reduce my risk of cancer if I found out I had a mutation.
- (6) I am too worried about the effects of knowing my results on women in my family.
- (7) Family members do not want me to get testing.
- (8) Risk to my insurance coverage.
- (9) Risk to my employment.
- (10) I am either too young or too old to benefit from knowing if I have a mutation.
- (11) I do not believe in obtaining personal genetic information.
- (12) Other (please describe) _____

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.

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		
		1	2	3	4	5	
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.
l.	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.
o.	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

Using the following scales, please circle your response for each question.

		<i>Not At All</i>					<i>Very Much</i>	<i>Not Applicable</i>	
1.	How distressing is it for you to know that you may be at increased risk for breast or ovarian cancer because of your family history?	1	2	3	4	5	-8	B 66.	
2.	How distressing is it to be given the opportunity to be tested for an altered BRCA-1/BRCA2, the altered genes associated with increased risk for breast and ovarian cancer?	1	2	3	4	5	-8	B 67.	
3.	How distressed do you expect to be if you get tested for an altered BRCA-1/BRCA2 gene (just before you receive results)?	1	2	3	4	5	-8	B 68.	
4.	How distressed would you be if you took the test and found that you had an altered BRCA-1/BRCA2 gene?	1	2	3	4	5	-8	B 69.	
5.	How distressed would you be if you took the test and found that you did not have an altered BRCA1/BRCA2 gene?	1	2	3	4	5	-8	B 70.	
6.	Overall, to what extent do you welcome the opportunity to be tested for an altered BRCA-1/BRCA2 gene?	1	2	3	4	5	-8	B 71.	

		<i>Not At All</i>			<i>All The Time</i>		
7.	How often do you worry about developing breast or ovarian cancer?	1	2	3	4	5	B 27.
8.	To what extent do these worries interfere with your every day life?	1	2	3	4	5	B 28.
9.	How often do you worry about having an altered gene which conveys heightened risk for breast and ovarian cancer ?	1	2	3	4	5	B 29.
10.	To what extent do these worries you have about having this altered gene interfere with your every day life?	1	2	3	4	5	B 30.

11. When was the last time you had a mammogram? B 32.

(Month/Year) _____ (-8) Does not apply because of surgery.

12. How many times have you conducted a breast self-examination in the past six months? B33.
 _____ times (-8) Does not apply because of surgery.

13. How confident are you that you will perform breast self examination (BSE) ---

13a. --as **frequently** as needed? (-8) Does Not Apply Because of Surgery. B34a.

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

13b. --as **carefully and competently** as needed? B34b.

(-8) Does Not Apply Because of Surgery

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

For each of the following areas of your life, we ask you to make **two** ratings. First, indicate how much these decisions have been affected by ***being at risk for breast or ovarian cancer*** (based on your family history). Second, how much these decisions would be affected by ***the results of genetic testing***?

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

		<u>Have been affected by being at risk for breast or ovarian cancer</u>					<u>Would be affected by the results of genetic testing</u>					
		1	2	3	4	5	1	2	3	4	5	
14.	Decisions about having children	1	2	3	4	5	1	2	3	4	5	B35a B35b
15.	Decisions about form of birth control	1	2	3	4	5	1	2	3	4	5	B36a B36b
16.	Decisions about which steps to take to prevent the occurrence of breast or ovarian cancer	1	2	3	4	5	1	2	3	4	5	B37a B37b
17.	Decisions about work and career	1	2	3	4	5	1	2	3	4	5	B38a B38b
18.	Decisions about savings and financial planning	1	2	3	4	5	1	2	3	4	5	B39a B39b
19.	Decisions about plans for the future	1	2	3	4	5	1	2	3	4	5	B40a B40b

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

Does Not Apply (Skip to the next question, 22)

B41.

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

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

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

B43.

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

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

B44.

23. Do you feel you are adequately informed about what you could do to reduce your risk of breast and ovarian cancer if you had an altered BRCA1/BRCA2 gene?

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

B45.

24. Do you feel you are adequately informed about the benefits and drawbacks of each option available to women who have an altered BRCA1/BRCA2 gene?

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

B46.

25. Do you feel you are adequately informed about what it would mean for your children if you had an altered BRCA1/BRCA2 gene?

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

B47.

26. How confident are you that you will make the best decision in deciding whether to be tested for BRCA1/BRCA2?

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

B48a.

27. How confident are you that you would cope effectively with a finding that you had an altered BRCA1/BRCA2 gene?

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

B48b.

28. How confident are you that you would make the best decision concerning your options if you were found to have an altered BRCA1/BRCA2 gene?

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

B48c.

29. How confident are you that you would be able to follow through and cope effectively over the long haul if you were found to have an altered BRCA1/BRCA2 gene?

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

B48d.

RELATIONSHIPS SECTION

1. Is there anyone in your life with whom you can share your most private feelings without holding back? C21.
(1) Yes (5) No
2. If married, can you share your most private feelings with your spouse/partner without holding back? C21a.
(1) Yes (5) No
3. If married, is there anyone besides your spouse/partner with whom you can share your most private feelings without holding back? C21b.
(1) Yes (5) No
-

LIFE EVENTS SECTION

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

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, please check the box and skip to page 11, Mood Section.

Not married or living with a partner

Ea.

Most people have disagreements in their relationships. Please indicate by circling the number that represents the extent of agreement or disagreement experienced between you and your spouse/partner **DURING THE PAST MONTH.**

		<i>Always Disagree</i>	<i>Almost Always Disagree</i>	<i>Frequently Disagree</i>	<i>Occasionally Disagree</i>	<i>Almost Always Agree</i>	<i>Always Agree</i>	
1.	Religious matters	1	2	3	4	5	6	H3.
2.	Demonstration of affection	1	2	3	4	5	6	H4.
3.	Sex relations	1	2	3	4	5	6	H6.
4.	Conventionality (correct or proper behavior)	1	2	3	4	5	6	H7.
5.	Making major decisions	1	2	3	4	5	6	H12.
6.	Career decisions	1	2	3	4	5	6	H15.

		<i>Never</i>	<i>Rarely</i>	<i>Occasionally</i>	<i>More often than most</i>	<i>Most of the time</i>	<i>All of the time</i>	
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 lived together)?	1	2	3	4	5	6	H20.
9.	How often do you and your partner quarrel?	1	2	3	4	5	6	H21.
10.	How often do you and your spouse/partner "get on each other's nerves?"	1	2	3	4	5	6	H22.

		<i>None of Them</i>	<i>Very Few of Them</i>	<i>Some of Them</i>	<i>Most of Them</i>	<i>All of Them</i>
11.	To what extent do you and your spouse/partner share interests together?	1	2	3	4	5

H24.

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

		<i>Never</i>	<i>Less than once a month</i>	<i>About twice a month</i>	<i>About twice a week</i>	<i>Once a day</i>	<i>More Often</i>
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 towards your spouse/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

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

H34.

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

17. The following questions concern your spouse/partner's involvement in your health care.

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

H35a.

H35b.

H35c.

H35d.

18. Has your spouse/partner attended individual, family or group sessions to become informed about your risk for breast or ovarian cancer and what can be done? H36.
(1) Yes (5) No

19. How much contact has your spouse/partner had with medical personnel concerning your risk for breast or ovarian cancer? H37.

Very Little
or None
1 2 3 4 5 6 A lot
7

20. Do you feel your spouse/partner is adequately informed concerning your risk for breast or ovarian cancer and what can be done about it? H38.

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

21. To what extent are you satisfied with your spouse/partner's involvement in your health care? H39.

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

MOOD SECTION

1. In the past year, have you had two weeks or more when nearly every day you felt sad, blue, or depressed or in which you lost all interest in things like work or hobbies or things you usually liked to do for fun? I12.
(1) Yes (5) No (Skip to Question 2)

1a. During this period, did your work or relationships suffer? I12a.
(1) Yes (5) No

1b. During this period, did you get counseling or psychotherapy? I12b.
(1) Yes (5) No

1c. During this period, did you get medication for this condition? I12c.
(1) Yes (5) No

2. Are you currently receiving counseling, psychotherapy, or medication for depression or emotional problems? I13.
(1) Yes (5) No

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**.*

		<u>Not at all</u>	<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	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 energy--slowed 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 or ovarian cancer. For each of the statements below, indicate the degree to which your life is affected positively by your risk of breast or ovarian cancer.

		<i>Not At All</i>	<i>A Very Small Degree</i>	<i>A Small Degree</i>	<i>A Moderate Degree</i>	<i>A Great Degree</i>	<i>A Very Great Degree</i>	
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	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 or ovarian 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. Please make your answers as true FOR YOU as you can.

		<i>I haven't been doing this at all</i> 1	<i>I've been doing this a little bit</i> 2	<i>I've been doing this some</i> 3	<i>I've been doing this a lot</i> 4	
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.
l.	I've been trying to come up with a strategy about what to do.	1	2	3	4	L7l.
m.	I've been getting comfort and understanding from someone.	1	2	3	4	L7m.

		<i>I haven't been doing this at all 1</i>	<i>I've been doing this a little bit 2</i>	<i>I've been doing this some 3</i>	<i>I've been doing this a lot 4</i>	
n.	I've been giving up the attempt to cope.	1	2	3	4	L7n.
o.	I've been accepting the possibility that I might have an altered gene.	1	2	3	4	L7o.
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 might have the 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.

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

Not married or living with a partner

(Skip to the last section on next page)

L8.

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

BACKGROUND DATA SECTION

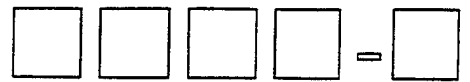
These are a few questions about your religious background that we forgot to ask on the original questionnaire.

1. Religion: Catholic (1) Protestant (4) **A3.**
Jewish (2) Buddhist (5)
Muslim (3) Other (6)
None (7)

- 1a. How often do you attend religious services? **A3a.**
(1) (5)
 Less Often Than Once a Month A Few Times A Month or More

- 1b. How important are religious and spiritual beliefs in your life? **A3b.**
Not at All Very Important
1 2 3 4 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 _____

ID _____

PRE-RESULTS QUESTIONNAIRE - A

You may notice that some of these questions were asked in previous questionnaires, but many of the questions are new. 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) Yes (5) No

2. Has any member of your family met with someone to have genetic counseling? **B25.**
(1) Yes (5) No

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

Decreased Very Much 1	Decreased Slightly 2	No Change 3	Increased Slightly 4	Increased Very Much 5
-------------------------------------	------------------------------------	---------------------------	------------------------------------	-------------------------------------

4. At this time, what is your decision regarding receiving your genetic results? **B112.**
(1) I will probably or definitely receive my results now, as soon as they are offered.
(Skip to Question 4)

(3) I do not intend to receive my results now, but may do so later. (Skip to Question 5)

(5) I do not intend to receive my results now or in the future. (Skip to Question 6)

5. If you will probably or definitely obtain your results ***now***, as soon as they are being offered to you, what are your reasons for doing so? **B113.**
(Please check all that apply and then circle the number of the statement which indicates your most important reason for receiving your results *now*).

(1) I just want to know whether I have the gene. I am happier knowing.

(2) In order to decide whether to get prophylactic surgery.

(3) To assist me in other medical decisions.

(4) To make decisions about family planning.

(5) To make decisions about financial planning and insurance.

(6) To make lifestyle and other non-medical decisions.

(7) To find out the risk that may be transmitted to my children.

(8) Family members want me to get testing.

(9) I want to help other family members by providing them with my results.

(10) Other (please describe) _____

6. If you do ***not*** intend to obtain your results ***now***, but may do so ***later***, please indicate your reasons. B114.

(Please check all that apply and then circle the number of the statement which indicates your most important reason for delaying receiving your results).

- (1) I am happier not knowing.
- (2) There are no decisions I need to make at this time for which knowledge of my results would be useful.
- (3) It would be too upsetting to learn that I have a mutation associated with increased risk of cancer.
- (4) Knowing that I have a mutation would interfere with my life as it is now.
- (5) There would not be much I could now do to reduce my risk of cancer if I found out I had a mutation.
- (6) I am too worried about the effects of knowing my results on women in my family.
- (7) Family members do not want me to get testing.
- (8) Family members want me to get testing, but I am not ready to do so.
- (9) I want to wait until there is less risk to insurance coverage.
- (10) I want to wait until there is less risk to employment.
- (11) I am either too young or too old to benefit from knowing if I have a mutation.
- (12) I want to wait until more is known about breast/ovarian cancer genes and what can be done to reduce a women's risk of cancer.
- (13) I simply am not ready to make up my mind at this time.
- (14) Other (please describe) _____

7. If you do ***not*** intend to obtain your results ***now or in the future***, please indicate your reasons. B115.

(Please check all that apply and then circle the number of the statement which indicates your most important reason for not receiving your results).

- (1) I am happier not knowing.
- (2) There are no decisions I need to make for which knowledge of my results would be useful.
- (3) It would be too upsetting to learn that I have a mutation associated with increased risk of cancer.
- (4) Knowing that I have a mutation would interfere with my life.
- (5) There would not be much I could do to reduce my risk of cancer if I found out I had a mutation.
- (6) I am too worried about the effects of knowing my results on women in my family.
- (7) Family members do not want me to get testing.
- (8) Risk to my insurance coverage.
- (9) Risk to my employment.
- (10) I am either too young or too old to benefit from knowing if I have a mutation.
- (11) I do not believe in obtaining personal genetic information.
- (12) Other (please describe) _____

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.

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		
		1	2	3	4	5	
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.
l.	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.
o.	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

Using the following scales, please circle your response for each question.

		<i>Not At All</i>					<i>Very Much</i>		<i>Not Appli- cable</i>	
		1	2	3	4	5	-8			
1.	How distressing is it for you to know that you may be at increased risk for recurrence of breast or ovarian cancer because of your family history?	1	2	3	4	5	-8		B66.	
2.	How distressing is it to be given the opportunity to be tested for an altered BRCA1/BRCA2, the altered genes associated with increased risk for breast and ovarian cancer?	1	2	3	4	5	-8		B67.	
3.	How distressed do you expect to be if you get tested for an altered BRCA1/BRCA2 gene (just before you receive results)?	1	2	3	4	5	-8		B68.	
4.	How distressed would you be if you took the test and found that you had an altered BRCA1/BRCA2 gene?	1	2	3	4	5	-8		B69.	
5.	How distressed would you be if you took the test and found that you did not have an altered BRCA1/BRCA2 gene?	1	2	3	4	5	-8		B70.	
6.	Overall, to what extent do you welcome the opportunity to be tested for an altered BRCA1/BRCA2 gene?	1	2	3	4	5	-8		B71.	

		<i>Not At All</i>			<i>All The Time</i>			
		1	2	3	4	5		
7.	How often do you worry about again developing breast or ovarian cancer?	1	2	3	4	5	B27.	
8.	To what extent do these worries interfere with your every day life?	1	2	3	4	5	B28.	
9.	How often do you worry about having an altered gene which conveys heightened risk for breast and ovarian cancer ?	1	2	3	4	5	B29.	
10.	To what extent do these worries you have about having this altered gene interfere with your every day life?	1	2	3	4	5	B30.	

11. When was the last time you had a mammogram? **B32.**

(Month/Year) _____ (-8) Does not apply because of surgery.

12. How many times have you conducted a breast self-examination in the past six months? B33.

_____ times (-8) Does not apply because of surgery.

13. How confident are you that you will perform breast self examination (BSE) ---

13a. --as **frequently** as needed? (-8) Does Not Apply Because of Surgery. B34a.

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

13b. --as **carefully and competently** as needed? B34b.

(-8) Does Not Apply Because of Surgery.

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

For each of the following areas of your life, we ask you to make **two** ratings. First, indicate how much these decisions have been affected by ***being at increased risk for breast or ovarian cancer*** (based on your family history). Second, how much these decisions would be affected by ***the results of genetic testing***?

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

		<u><i>Have been affected by being at increased risk for breast or ovarian cancer</i></u>					<u><i>Would be affected by the results of genetic testing</i></u>					
		1	2	3	4	5	1	2	3	4	5	
14.	Decisions about having children											B35a B35b
15.	Decisions about form of birth control											B36a B36b
16.	Decisions about which steps to take to prevent the recurrence of breast or ovarian cancer											B37a B37b
17.	Decisions about work and career											B38a B38b
18.	Decisions about savings and financial planning											B39a B39b
19.	Decisions about plans for the future											B40a B40b

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

Does Not Apply (Skip to the next question, 22)

B41.

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

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

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

B43.

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

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

B44.

23. Do you feel you are adequately informed about what you could do to reduce your risk of recurrence of breast and ovarian cancer if you had an altered BRCA1/BRCA2 gene?

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

B45.

24. Do you feel you are adequately informed about the benefits and drawbacks of each option available to women who have an altered BRCA1/BRCA2 gene?

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

B46.

25. Do you feel you are adequately informed about what it would mean for your children if you had an altered BRCA1/BRCA2 gene?

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

B47.

26. How confident are you that you will make the best decision in deciding whether to be tested for BRCA1/BRCA2?

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

B48a.

27. How confident are you that you would cope effectively with a finding that you had an altered BRCA1/BRCA2 gene?

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

B48b.

28. How confident are you that you would make the best decision concerning your options if you were found to have an altered BRCA1/BRCA2 gene?

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

B48c.

29. How confident are you that you would be able to follow through and cope effectively over the long haul if you were found to have an altered BRCA1/BRCA2 gene?

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

B48d.

RELATIONSHIPS SECTION

1. Is there anyone in your life with whom you can share your most private feelings without holding back? C21.
(1) Yes (5) No
2. If married, can you share your most private feelings with your spouse/partner without holding back? C21a.
(1) Yes (5) No
3. If married, is there anyone besides your spouse/partner with whom you can share your most private feelings without holding back? C21b.
(1) Yes (5) No
-

LIFE EVENTS SECTION

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

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, please check the box and skip to page 11, Mood Section.

Not married or living with a partner

Ea.

Most people have disagreements in their relationships. Please indicate by circling the number that represents the extent of agreement or disagreement experienced between you and your spouse/partner **DURING THE PAST MONTH.**

		<i>Always Disagree</i>	<i>Almost Always Disagree</i>	<i>Frequently Disagree</i>	<i>Occasionally Disagree</i>	<i>Almost Always Agree</i>	<i>Always Agree</i>	
1.	Religious matters	1	2	3	4	5	6	H3.
2.	Demonstration of affection	1	2	3	4	5	6	H4.
3.	Sex relations	1	2	3	4	5	6	H6.
4.	Conventionality (correct or proper behavior)	1	2	3	4	5	6	H7.
5.	Making major decisions	1	2	3	4	5	6	H12.
6.	Career decisions	1	2	3	4	5	6	H15.

		<i>Never</i>	<i>Rarely</i>	<i>Occasionally</i>	<i>More often than most</i>	<i>Most of the time</i>	<i>All of the time</i>	
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 lived together)?	1	2	3	4	5	6	H20.
9.	How often do you and your partner quarrel?	1	2	3	4	5	6	H21.
10.	How often do you and your spouse/partner "get on each other's nerves?"	1	2	3	4	5	6	H22.

		<i>None of Them</i>	<i>Very Few of Them</i>	<i>Some of Them</i>	<i>Most of Them</i>	<i>All of Them</i>
11.	To what extent do you and your spouse/partner share interests together?	1	2	3	4	5

H24.

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

		<i>Never</i>	<i>Less than once a month</i>	<i>About twice a month</i>	<i>About twice a week</i>	<i>Once a day</i>	<i>More Often</i>
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 towards your spouse/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

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

H34.

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

17. The following questions concern your spouse/partner's involvement in your health care.

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

H35a.

H35b.

H35c.

H35d.

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.*

		<i>Not at all</i>	<i>A little</i>	<i>Quite a bit</i>	<i>Extremely</i>	
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 energy--slowed 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 or ovarian cancer. For each of the statements below, indicate the degree to which your life is affected positively by your risk of breast or ovarian cancer.

		<i>Not At All</i>	<i>A Very Small Degree</i>	<i>A Small Degree</i>	<i>A Moderate Degree</i>	<i>A Great Degree</i>	<i>A Very Great Degree</i>	
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	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 or ovarian 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. Please make your answers as true FOR YOU as you can.

		<i>I haven't been doing this at all 1</i>	<i>I've been doing this a little bit 2</i>	<i>I've been doing this some 3</i>	<i>I've been doing this a lot 4</i>	
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.
l.	I've been trying to come up with a strategy about what to do.	1	2	3	4	L7l.
m.	I've been getting comfort and understanding from someone.	1	2	3	4	L7m.

		<i>I haven't been doing this at all</i> 1	<i>I've been doing this a little bit</i> 2	<i>I've been doing this some</i> 3	<i>I've been doing this a lot</i> 4	
n.	I've been giving up the attempt to cope.	1	2	3	4	L7n.
o.	I've been accepting the possibility that I might have an altered gene.	1	2	3	4	L7o.
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 might have the 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.

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

Not married or living with a partner

(Skip to the last section on next page)

L8.

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

BACKGROUND DATA SECTION

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

1. Religion:
- | | | | | | | |
|----------|-----|--------------------------|------------|-----|--------------------------|------|
| Catholic | (1) | <input type="checkbox"/> | Protestant | (4) | <input type="checkbox"/> | A 3. |
| Jewish | (2) | <input type="checkbox"/> | Buddhist | (5) | <input type="checkbox"/> | |
| Muslim | (3) | <input type="checkbox"/> | Other | (6) | <input type="checkbox"/> | |
| | | | None | (7) | <input type="checkbox"/> | |
-
- 1a. How often do you attend religious services? A 3a.
- (1) (5)
- Less Often Than Once a Month A Few Times A Month or More
-
- 1b. How important are religious and spiritual beliefs in your life? A 3b.
- Not at All 2 3 4 Very Important
1 5

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



WOMEN'S HEALTH STUDY
Brother Questionnaire

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) I 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)		B92a.
b.	Mother		B92b.
c.	Grandmother(s) Maternal		B92c1.
d.	Grandmother(s) Paternal		B92c2.
e.	Aunt(s) Maternal		B92d1.
f.	Aunt(s) Paternal		B92d2.
g.	Cousin(s) Maternal		B92e1.
h.	Cousin(s) Paternal		B92e2.
i.	Wife		B92f.
j.	Daughter(s)		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) I Don't Know

IF ANSWERED NO, GO TO QUESTION 7

4. How distressing is it for you to know that women in your family may be at increased risk for breast cancer because of their family history?

B66a.

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.)

		<i>Yes</i>	<i>No</i>	<i>Not Applicable</i>	
a.	Mother	1	5	9	B93a.
b.	Grandmother(s)	1	5	9	B93b.
c.	Aunt(s)	1	5	9	B93c.
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** (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.

Not 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?

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		<i>I Don't Know</i>	
		1	2	3	4	5	9	
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	B20b.
c.	Mammography can detect lumps that cannot be felt by a woman or by her doctor.	1	2	3	4	5	9	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 an altered gene (BRCA-1 or BRCA-2) 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.
 (1) Yes (5) No

3. Were you aware that **men** are being offered the opportunity to take this test? B77b.
 (1) Yes (5) No

4. 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.)

		<i>Yes</i>	<i>No</i>	<i>Not Applicable</i>	
a.	Sister(s)	1	5	9	B95a.
b.	Mother	1	5	9	B95b.
c.	Grandmother(s)	1	5	9	B95c.
d.	Aunt(s)	1	5	9	B95d.
e.	Cousin(s)	1	5	9	B95e.
f.	Wife	1	5	9	B95f.
f.	Daughter(s)	1	5	9	B95g.
g.	Other women family members	1	5	9	B95h.

5. 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) 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 definitely take the test soon.
- (2)_____ I will definitely take the test, but I am not sure when.
- (3)_____ I will probably take the test.
- (4)_____ I am undecided whether I will take the test.
- (5)_____ I will probably not take the test.
- (6)_____ I will definitely not take the test.

9. If you think you will probably or definitely take the test, what are your reasons for doing so?
(Please check **all that apply**).

B16a.

- (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 an altered gene.
- (6)_____ I am worried about my own risk for cancer.
- (7)_____ Other (describe) _____

10. If you **do not** think you will probably or definitely take the test, what are your reasons for **not** doing so? (Please check all that apply).

B17a.

- (1)_____ I am happier not knowing.
- (2)_____ I do not see any reason for learning if I have an altered gene.
- (3)_____ It would be too upsetting to learn that I have an altered gene.
- (4)_____ I am too worried about women in my family.
- (5)_____ I believe I already know whether I have an altered gene.
- (6)_____ There would not be much I could do if I found out I had an altered gene.
- (7)_____ I do not feel able emotionally to deal with testing.
- (8)_____ Family members do not want me to get testing.
- (9)_____ Risk to my insurance coverage.
- (10)_____ Too much hassle
- (11)_____ Other (describe) _____

11. How distressing is it for you to know that you may carry an altered gene which conveys an increased risk of breast cancer?

B76.

Not At All Distressed					Very Distressed	
1	2	3	4	5		

12. Overall, how important are the opinions of the following family members in your decision whether to be tested for an altered gene associated with increased risk of breast cancer?

		Not At All	A Little	Some-what	A Great Deal	Not Applicable
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.

B78b.

B78c.

B78d.

B78e.

13. How pressured do you feel from the following family members to get tested for an 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 Applicable
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.

14. How much of a **burden** is it **on you** when the women in your family pressure you to get tested for an altered gene?

B80.

No Burden	A Little Burden	Some Burden	A Great Burden	Not applicable, No Pressure
1	2	3	4	5

15. How distressed would you be if you took the test and found that you **did not** have an 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 **did not have** an altered gene which conveys increased risk for breast cancer, what would you expect your reactions to be?

		Strongly Disagree			Strongly 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

B81a.
B81b.
B81c.
B81d.
B81e.
B81f.
B81g.

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		
		1	2	3	4	5	
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** an altered gene which conveys increased risk for breast cancer? **B69a.**

Not At All Distressed					Very Distressed	
1	2	3	4	5		

18. If you were to take the test and find out that you **had** an altered gene, what would you expect your reactions to be?

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		
		1	2	3	4	5	
a.	I would feel relieved about being more certain.	1	2	3	4	5	B82a.
b.	I would feel I had been told what I knew all along.	1	2	3	4	5	B82b.
c.	I would not believe the results.	1	2	3	4	5	B82c.
d.	I would feel guilty.	1	2	3	4	5	B82d.
e.	I would be depressed.	1	2	3	4	5	B82e.
f.	I would feel worried about the future.	1	2	3	4	5	B82f.
g.	I would just fall apart emotionally.	1	2	3	4	5	B82g.
h.	I would feel anxious.	1	2	3	4	5	B82h.
i.	I would feel angry.	1	2	3	4	5	B82i.
j.	I would not feel very differently.	1	2	3	4	5	B82j.

		<i>Not At All</i>					<i>All The Time</i>				
19.	How often do you worry about having an altered gene associated with risk for breast cancer among women?	1	2	3	4	5	B83.				
20.	To what extent do any worries you have about this genetic alteration interfere with every day life?	1	2	3	4	5	B84.				
21.	How often do you worry about women in your family developing breast cancer?	1	2	3	4	5	B85.				
22.	How often do you worry about developing cancer yourself?	1	2	3	4	5	B86.				
23.	How much do worries about developing cancer interfere with your everyday life?	1	2	3	4	5	B87.				

24. How likely do you think it is that you have an 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 an altered gene which conveys increased risk for breast cancer in women relatives? B89.

Not At All	A Little	Somewhat	A Great Deal	I Don't Know
1	2	3	4	5

26. 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.***

		<u>Not at all</u>	<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	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 energy--slowed 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 share your most private feelings without holding back? C21.

(1) Yes (5) No

1a. Do you have that kind of relationship with **your sister** (who gave us your name)? C21c.

(1) Yes (5) No

2. How often do you talk to your sister? (**check one**) C22.

- | | |
|-------------------------------|----------------------------------|
| (1) _____ Most every day | (5) _____ Less than once a month |
| (2) _____ A few times a week | (6) _____ Less than once a year |
| (3) _____ A few times a month | (7) _____ Never |
| (4) _____ Once a month | |

3. Please indicate the extent to which each of the following items currently describes **the family in which you grew up.**

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		
		1	2	3	4	5	
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	M3.
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	M6.
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	M9.
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.
3l.	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 A 1.
2. Ethnic Background: White 1 Black 4 A 2.
 Hispanic 2 Asian 5
 Native American 3 Other 6
3. Religion: Catholic 1 Protestant 4 A 3.
 Jewish 2 Buddhist 5
 Muslim 3 Other 6
 None 7
- 3a. How often do you attend religious services? A 3a.
 1 Less Than Once a Month 5 A Few Times A Month or More
- 3b. How important are religious and spiritual beliefs in your life? A 3b.
 Not at All Very Important
 1 2 3 4 5
4. Are you currently (please check one)? A 4.
 1 Single
 2 Married
 3 Not married, but living in a steady,
 marriage-like relationship
 4 Separated
 5 Divorced
 6 Widowed
5. If you **are** currently married, what was the date of your current marriage? A 5.
 Month _____ Year _____
- 5a. Is this your first marriage? (1) Yes (5) No A 5a.
6. How many children do you have? _____ A 6.
 6a. Number of children living at home? _____ A 6a.
 6b. Number who are under age 6? _____ A 6b.
 6c. Number of Daughters? _____ A 6c.
7. Do you plan to have more children? (1) Yes (5) No (3) Undecided A 12.
- 7a. If yes, how many more children? _____ A 12a.

8. In general, would you say your health is: I1.
- Excellent (1) Very Good (2) Good (3) Fair (4) Poor (5)
9. Are you currently working for pay outside the home? A7.
- (1) Yes (5) No
10. If **yes**, about how many hours per week are you working for pay? A8.
- Less than 10 10-20 21-30 31-40 41 or more
- (1) (2) (3) (4) (5)
11. What is the highest level of education you have completed? (Check one) A9.
- 1 Less than 9th grade 5 Completed college
 2 Dropped out of high school 6 Some graduate or professional training
 3 Completed high school 7 Completed graduate or professional training
 4 Some college

The following two questions are optional, but we hope that you will provide this information.

12. What is your household's total income? (Check one) A10.
- (1) Less than \$10,000 (4) \$30,000 to \$39,999 (7) \$60,000 to \$69,999
 (2) \$10,000 to \$19,999 (5) \$40,000 to \$49,999 (8) Greater than \$69,999
 (3) \$20,000 to \$29,999 (6) \$50,000 to \$59,999
13. How many people (adults and children) does this income support? _____ A11.
-

THANK YOU VERY MUCH FOR YOUR PARTICIPATION.

-



WOMEN'S HEALTH STUDY
Sister Questionnaire

Today's Date _____

ID _____

SISTER QUESTIONNAIRE

HEALTH SECTION

1. Have you ever been diagnosed with Breast cancer? (1) Yes (5) No **B 1 u.**
2. Have you ever been diagnosed with Ovarian cancer? (1) Yes (5) No **B 5.**

Please answer the following questions only if you have been diagnosed at any time with breast or ovarian cancer.

I have never been diagnosed with breast or ovarian cancer. Skip to 11

3. When were you first diagnosed with breast cancer? **B 1.**
Month _____ Year _____ Not Applicable
4. When were you first diagnosed with ovarian cancer? **B 5a.**
Month _____ Year _____ Not Applicable
5. Have you received any of the following treatments?
- | | | | |
|--------------|----------------------------------|---------------------------------|--------------|
| Chemotherapy | (1) <input type="checkbox"/> Yes | (5) <input type="checkbox"/> No | B 4a. |
| Radiation | (1) <input type="checkbox"/> Yes | (5) <input type="checkbox"/> No | B 4b. |
| Surgery | (1) <input type="checkbox"/> Yes | (5) <input type="checkbox"/> No | B 4c. |
6. Have you ever had any of the following surgical procedures?
- 6a. **Lumpectomy** (Removal of lump from breast) **B 6a.**
(1) Yes (5) No If yes, when? Month _____ Year _____ **B 6a2.**
- 6b. **Unilateral mastectomy** (Removal of one breast) **B 6c.**
(1) Yes (5) No If yes, when? Month _____ Year _____ **B 6c2.**
- 6c. **Bilateral mastectomy** (Removal of both breasts) **B 6e.**
(1) Yes (5) No If yes, when? Month _____ Year _____ **B 6e2.**
- 6d. **Hysterectomy** (Removal of uterus) **B 6d.**
(1) Yes (5) No If yes, when? Month _____ Year _____ **B 6d2.**
- 6e. **Oophorectomy** (Removal of ovaries) **B 6b.**
(1) Yes (5) No If yes, when? Month _____ Year _____ **B 6b2.**

7. Do you currently consider yourself in remission? B 3.
 (1) Yes (5) No (3) I Don't Know

8. Have you ever had a recurrence of breast or ovarian cancer? B 100.
 (1) Yes (5) No (3) I Don't Know

9. Before your diagnosis of breast cancer, how likely did you think you were to develop breast cancer, compared to **the average woman**? (Please circle one) B 7.

Much Less Likely		Much More Likely		
1	2	3	4	5

10. Before your diagnosis of breast cancer, how likely did you think you were to develop breast cancer, compared to **the women in your family**? (Please circle one) B 8.

Much Less Likely		Much More Likely		
1	2	3	4	5

*Skip to
Question 13*

11. How likely did you think you are to develop breast cancer, compared to **the average woman**? (Please circle one) B 7a.

Much Less Likely		Much More Likely		
1	2	3	4	5

12. How likely did you think you are to develop breast cancer, compared to **the women in your family**? (Please circle one) B 8a.

Much Less Likely		Much More Likely		
1	2	3	4	5

13. When was the last time you had a mammogram? B 32.
 _____ Month _____ Year This question does not apply because of surgery.
 (-8)

14. How many times have you conducted a breast self-examination (BSE) in the past six months? B 33.
 _____ times This question does not apply because of surgery.
 (-8)

15. In general, would you say your health is: 11.
- Excellent (1)
 Very Good (2)
 Good (3)
 Fair (4)
 Poor (5)

16. Compared to one year ago, how would you rate your health in general now? 12.
(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 HISTORY SECTION

In the next set of questions, 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) I Don't Know
2. If Yes, how many of the following relatives been affected by (diagnosed with) breast cancer? *(How many relatives for each category where applicable?)*

	<u>Relative:</u>	<u>How Many?</u>	
a.	Sister(s)		B92a.
b.	Mother		B92b.
c.	Grandmother(s) Maternal		B92c1.
d.	Grandmother(s) Paternal		B92c2.
e.	Aunt(s) Maternal		B92d1.
f.	Aunt(s) Paternal		B92d2.
g.	Cousin(s) Maternal		B92e1.
h.	Cousin(s) Paternal		B92e2.
i.	Wife		B92f.
j.	Daughter(s)		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) I Don't Know

IF ANSWERED NO, GO TO QUESTION 7

4. How distressing is it for you to know that women in your family may be at increased risk for breast cancer because of their family history?

B66a.

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.)

		<i>Yes</i>	<i>No</i>	<i>Not Applicable</i>	
a.	Mother	1	5	9	B93a.
b.	Grandmother(s)	1	5	9	B93b.
c.	Aunt(s)	1	5	9	B93c.
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 for 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 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.

Not 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?

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		<i>I Don't Know</i>	
		1	2	3	4	5	9	
a.	Mammography is effective in the early detection of breast cancer in women.							B20a.

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		<i>I Don't Know</i>	
		1	2	3	4	5	9	
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	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 an altered gene (BRCA-1 or BRCA-2) 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.
 (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.)

		<i>Yes</i>	<i>No</i>	<i>Not Applicable</i>	
a.	Sister(s)	1	5	9	B95a.
b.	Mother	1	5	9	B95b.
c.	Grandmother(s)	1	5	9	B95c.
d.	Aunt(s)	1	5	9	B95d.
e.	Cousin(s)	1	5	9	B95e.
f.	Wife	1	5	9	B95f.
f.	Daughter(s)	1	5	9	B95g.
g.	Other women family members	1	5	9	B95h.

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 testing? **B98.**

(1) Yes (5) No (3) No Opinion

6. How often do you discuss genetic testing for breast cancer with **your sister** (who gave us your name)? **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? **B15c.**
(Please check one response).

- (1) _____ I will definitely take the test soon.
 (2) _____ I will definitely take the test, but I am not sure when.
 (3) _____ I will probably take the test.
 (4) _____ I am undecided whether I will take the test.
 (5) _____ I will probably not take the test.
 (6) _____ I will definitely not take the test.

8. If you think you will probably or definitely take the test, what are your reasons for doing so? **B16a.**
(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 an altered gene.
- (6)_____ I am worried about my own risk for cancer.
- (7)_____ Other (describe) _____

9. If you **do not** think you will probably or definitely take the test, what are your reasons for **not** doing so? **(Please check all that apply).** **B17a.**

- (1)_____ I am happier not knowing.
- (2)_____ I do not see any reason for learning if I have an altered gene.
- (3)_____ It would be too upsetting to learn that I have an altered gene.
- (4)_____ I am too worried about women in my family.
- (5)_____ I believe I already know whether I have an altered gene.
- (6)_____ There would not be much I could do if I found out I had an altered gene.
- (7)_____ I do not feel able emotionally to deal with testing.
- (8)_____ Family members do not want me to get testing.
- (9)_____ Risk to my insurance coverage.
- (10)_____ Too much hassle
- (11)_____ Other (describe) _____

10. How distressing is it for you to know that you may carry an altered gene which conveys an increased risk of breast cancer? **B76.**

Not At All Distressed					Very Distressed	
1	2	3	4	5		

11. Overall, how important are the opinions of the following family members in your decision whether to be tested for an altered gene associated with increased risk for breast cancer? (Circle *Not Applicable* if you do not have any relatives in that category.)

		Not At All	A Little	Some-what	A Great Deal	Not Applicable
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.

B78b.

B78c.

B78d.

B78e.

12. How pressured do you feel from the following family members to get tested for an 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 Applicable
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.

13. How much of a **burden** is it **on you** when the women in your family pressure you to get tested for an altered gene?

B80.

No Burden	A Little Burden	Some Burden	A Great Burden	Not applicable, 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 an 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 **did not have** an altered gene which conveys increased risk for breast cancer, what would you expect your reactions to be?

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		
		1	2	3	4	5	
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** an altered gene which conveys increased risk for breast cancer? B69a.

Not At All Distressed					Very Distressed	
1	2	3	4	5		

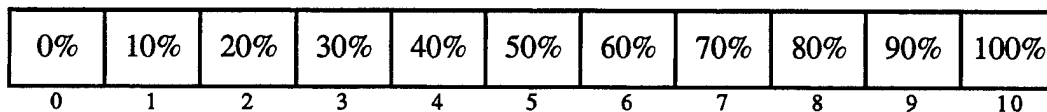
17. If you were to take the test and find out that you **had** an altered gene, what would you expect your reactions to be?

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		
		1	2	3	4	5	
a.	I would feel relieved about being more certain.	1	2	3	4	5	B82a.
b.	I would feel I had been told what I knew all along.	1	2	3	4	5	B82b.
c.	I would not believe the results.	1	2	3	4	5	B82c.
d.	I would feel guilty.	1	2	3	4	5	B82d.
e.	I would be depressed.	1	2	3	4	5	B82e.
f.	I would feel worried about the future.	1	2	3	4	5	B82f.
g.	I would just fall apart emotionally.	1	2	3	4	5	B82g.

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		
		1	2	3	4	5	
h.	I would feel anxious.	1	2	3	4	5	B82h.
i.	I would feel angry.	1	2	3	4	5	B82i.
j.	I would not feel very differently.	1	2	3	4	5	B82j.

		<i>Not At All</i>			<i>All The Time</i>		
		1	2	3	4	5	
18.	How often do you worry about having an altered gene associated with risk for breast cancer among women?	1	2	3	4	5	B83.
19.	To what extent do any worries you have about this genetic alteration interfere with every day life?	1	2	3	4	5	B84.
20.	How often do you worry about women in your family developing breast cancer?	1	2	3	4	5	B85.
21.	How often do you worry about developing cancer yourself?	1	2	3	4	5	B86.
22.	How much do worries about developing cancer interfere with your everyday life?	1	2	3	4	5	B87.

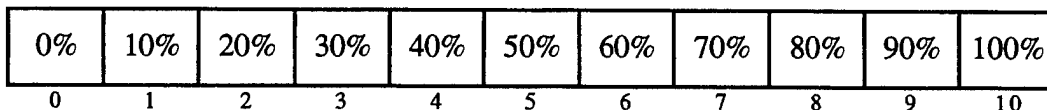
23. How likely do you think it is that you have an altered gene which conveys increased risk for breast cancer in women relatives? (Please circle one) **B88.**



24. How much would it affect your health in the future if you had an 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)

25. Overall, what do you think your risk is of developing cancer (or developing cancer again) in the future? **B90.**



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.*

		<u>Not at all</u>	<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	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 energy--slowed 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**.

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		
		1	2	3	4	5	
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	M3.
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	M6.
g.	There are lots of bad feelings in the family.	1	2	3	4	5	M7.
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	M9.
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.
l.	We confide in each other.	1	2	3	4	5	M12.

2. Is there anyone in your life with whom you can share your most private feelings without holding back? C21.

Yes No

- 2a. Do you have that kind of relationship with **your sister** (who gave us your name)? C21c.

Yes No

3. How often do you talk to **your sister**? (check one) C22.

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

BACKGROUND DATA SECTION

Now, we'd like to know more about you.

1. Date of Birth _____ Month _____ Day _____ Year **A1.**
2. Ethnic Background: White 1 Black 4 **A2.**
 Hispanic 2 Asian 5
 Native American 3 Other 6
3. Religion: Catholic 1 Protestant 4 **A3.**
 Jewish 2 Buddhist 5
 Muslim 3 Other 6
 None 7
- 3a. How often do you attend religious services? **A3a.**
 1 Less Than Once a Month 5 A Few Times A Month or More
- 3b. How important are religious and spiritual beliefs in your life? **A3b.**
 Not at All 1 2 3 4 5 Very Important
4. Are you currently (**please check one**)? 1 Single **A4.**
 2 Married
 3 Not married, but living in a steady,
 marriage-like relationship
 4 Separated
 5 Divorced
 6 Widowed
5. If you **are** currently married, what was the date of your current marriage? **A5.**
 Month _____ Year _____
- 5a. Is this your first marriage? (1) Yes (5) No **A5a.**
6. How many children do you have? _____ **A6.**
 6a. Number of children living at home? _____ **A6a.**
 6b. Number who are under age 6? _____ **A6b.**
 6c. Number of Daughters? _____ **A6c.**
7. Do you plan to have more children? (1) Yes (5) No (3) Undecided **A12.**
 7a. If yes, how many more children? _____ **A12a.**

8. Are you currently working for pay outside the home? A 7.
 (1) Yes (5) No
9. If yes, about how many hours per week are you working for pay? A 8.
 Less than 10 10-20 21-30 31-40 41 or more

 (1) (2) (3) (4) (5)
10. What is the highest level of education you have completed? (Check one) A 9.
- | | |
|---|--|
| 1 <input type="checkbox"/> Less than 9th grade | 5 <input type="checkbox"/> Completed college |
| 2 <input type="checkbox"/> Dropped out of high school | 6 <input type="checkbox"/> Some graduate or professional training |
| 3 <input type="checkbox"/> Completed high school | 7 <input type="checkbox"/> Completed graduate or professional training |
| 4 <input type="checkbox"/> Some college | |

The following two questions are optional, but we hope that you will provide this information.

11. What is your household's total income? (Check one) A 10.
- | | | |
|---|---|--|
| (1) <input type="checkbox"/> Less than \$10,000 | (4) <input type="checkbox"/> \$30,000 to \$39,999 | (7) <input type="checkbox"/> \$60,000 to \$69,999 |
| (2) <input type="checkbox"/> \$10,000 to \$19,999 | (5) <input type="checkbox"/> \$40,000 to \$49,999 | (8) <input type="checkbox"/> Greater than \$69,999 |
| (3) <input type="checkbox"/> \$20,000 to \$29,999 | (6) <input type="checkbox"/> \$50,000 to \$59,999 | |
12. How many people (adults and children) does this income support? _____ A 11.

**THANK YOU VERY MUCH
FOR YOUR PARTICIPATION.**

POST-RESULTS 1: *One to Two Months*

Genetic Testing Section

1. When did you receive your results of genetic testing? _____ B101

2. Are you the only person in your family who has gotten genetic testing for breast and ovarian cancer?
 (1) Yes (5) No B101a

3. What were the results of testing? B101b

1 Negative (uninformative) for BRCA1/BRCA2 and all Family members who were tested were negative for BRCA1/BRCA2 OR you are the only person in your family who has gotten testing (Skip to Question 4)

2 Negative (informative) for BRCA1/BRCA2, but at least one family member was found to be Positive (Skip to Question 4)

3 Positive for BRCA1/BRCA2 (Skip to Next page, Question 5)

4. When you took the test and found out that you did not have an altered gene associated with high risk for breast and ovarian cancer, what were your reactions?

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>			<i>N/A</i>	
		1	2	3	4	5			
a.	I felt wonderful.	1	2	3	4	5	-8	B18a_a.	
b.	I felt I had been told what I knew all along.	1	2	3	4	5	-8	B18a_b.	
c.	I felt relieved.	1	2	3	4	5	-8	B18a_c.	
d.	I did not believe the results.	1	2	3	4	5	-8	B18a_d.	
e.	I fell apart emotionally.	1	2	3	4	5	-8	B18a_e.	
f.	I felt guilty.	1	2	3	4	5	-8	B18a_f.	
g.	I still felt anxious.	1	2	3	4	5	-8	B18a_g.	
h.	I felt angry.	1	2	3	4	5	-8	B18a_h.	
i.	I felt prepared for the future.	1	2	3	4	5	-8	B18a_i.	
j.	I felt I had done all I needed to do.	1	2	3	4	5	-8	B18a_j.	
k.	I did not feel very differently.	1	2	3	4	5	-8	B18a_k.	

INTERVIEWER: Skip to Page 3, Question 6

5. When you took the test and found out that you **had** an altered gene associated with high risk for breast and ovarian cancer, what were your reactions?

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		<i>N/A</i>	
		1	2	3	4	5		
a.	I felt relieved about being more certain.	1	2	3	4	5	-8	B19a_a.
b.	I felt I had been told what I knew all along.	1	2	3	4	5	-8	B19a_b.
c.	I did not believe the results.	1	2	3	4	5	-8	B19a_c.
d.	I felt guilty.	1	2	3	4	5	-8	B19a_d.
e.	I felt depressed.	1	2	3	4	5	-8	B19a_e.
f.	I felt worried about the future.	1	2	3	4	5	-8	B19a_f.
g.	I fell apart emotionally.	1	2	3	4	5	-8	B19a_g.
h.	I felt anxious.	1	2	3	4	5	-8	B19a_h.
i.	I felt angry.	1	2	3	4	5	-8	B19a_i.
j.	I did not feel very differently.	1	2	3	4	5	-8	B19a_j.
k.	[For those who have daughters]. I wanted my daughters to be tested as soon as possible.	1	2	3	4	5	-8	B19a_k.

6. I am going to read a list of comments made by people after they have received their genetic test results. When you hear each comment, think about your thoughts and feelings toward the test results in terms of you. Please tell me how often each of the comments was true for you since you have received your test results, with the choices of *Not at All*, *Rarely*, *Sometimes*, and *Often*.

(INTERVIEWER NOTE: "IT" in the following questions refers to "RECEIVING TEST RESULTS")

		Not at All	Rarely	Sometimes	Often	
a.	I thought about it when I didn't mean to.	0	1	3	5	B116a.
b.	I avoided letting myself get upset when I thought about it or was reminded of it.	0	1	3	5	B116b.
c.	I tried to remove it from memory.	0	1	3	5	B116c.
d.	I had trouble falling asleep or staying asleep, because of pictures or thoughts about it that came into my mind.	0	1	3	5	B116d.
e.	I had waves of strong feelings about it.	0	1	3	5	B116e.
f.	I had dreams about it.	0	1	3	5	B116f.
g.	I stayed away from reminders of it.	0	1	3	5	B116g.
h.	I felt as if it hadn't happened or it wasn't real.	0	1	3	5	B116h.
i.	I tried not to talk about it.	0	1	3	5	B116i.
j.	Pictures about it popped into my mind.	0	1	3	5	B116j.
k.	Other things kept making me think about it.	0	1	3	5	B116k.
l.	I was aware that I still had a lot of feelings about it, but I didn't deal with them	0	1	3	5	B116l.
m.	I tried not to think about it.	0	1	3	5	B116m.
n.	Any reminder brought back feelings about it.	0	1	3	5	B116n.
o.	My feelings about it were kind of numb.	0	1	3	5	B116o.

Please answer the following two questions using a 1-5 scale, where 1=Not at All and 5=All the time

		<i>Not At All</i>			<i>All The Time</i>		
7	How often do you worry about developing breast cancer OR developing breast cancer again?	1	2	3	4	5	B27.
8.	To what extent do these worries interfere with your every day life?	1	2	3	4	5	B28.

Symptoms of Strain Section

LISTED BELOW ARE SOME SYMPTOMS OF STRAIN THAT PEOPLE SOMETIMES HAVE. Please listen to each one carefully and tell me the answer which best reflects how much that symptom has bothered you during the **PAST THREE MONTHS**. Please use the following scale: 1=Not at all, 2=A little, 3=Quite a bit, and 4=Extremely.

		<i>Not at all</i>	<i>A little</i>	<i>Quite a bit</i>	<i>Extremely</i>	
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 energy--slowed 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.
19.	Feeling blue	1	2	3	4	K19.
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.

26. Are the symptoms we just talked about related to your receiving your genetic test results?

Yes	No
1	5

K26

Open-ended Questions:

1. Do you feel you were given adequate information before receiving your genetic results? B117.

1a. Was there anything omitted that would have been helpful? B117a.

1b. What information was most helpful? B117b.

2. What was the most effective or helpful thing you did to cope during this process?

B118.

3. Were there any things you did that were not helpful? What were they?

B119.

4. Who has been the most helpful during this time? (Make a listing in order R gives you)

B120.

- | | |
|----------|----------|
| 1. _____ | 5. _____ |
| 2. _____ | 6. _____ |
| 3. _____ | 7. _____ |
| 4. _____ | 8. _____ |

4a. If the list has more than one person, Who has been most helpful?

B120a.

4b. What did they do for you?

B120b.

5. Has there been anything someone did that was not helpful?

B121.

6. Are you currently Married or Living in a steady marriage-like relationship?

B122.

(1) Yes

(5) No (Skip to next page, question 9)

If YES and R has not yet discussed her spouse/partner's support:

7. What's the most helpful thing your spouse/partner has done or is doing for you?

B123.

8. What's the most helpful thing your spouse could do for you?

B124.

9. Is there anything you plan to do immediately with this information?

B125.

10. What would you tell someone who is contemplating genetic testing?

B126.

11. Do you have any regrets about getting this testing? If yes, what are they?

B127.

12. Are you the first person in your family to get testing?

13. Will you encourage your relatives to get genetic testing or discourage them from testing?

14. We are trying to get a better picture of this process. What is something I didn't ask you that I should have?

POST-RESULTS INTERVIEW--*Six Month Follow-Up*

INTERVIEWER: For the Introduction, Please include the following important points or read the script:

- Thank the subject again for her participation (We know we've asked a lot of her.)
- This interview is 6 months after receiving genetic test results.
- Repetition of Questions needed to compare results to our previous research and to other researchers.
- Remind subject that this interview is confidential and completely voluntary.
- Suggest that the subject may prefer to get a pen and paper to jot down the different scales that will be used.

We have asked you a lot of questions over the last several years while you were waiting for your genetic results. This interview is scheduled 6 months after you received genetic test results. We recognize that we asked many of these questions before. They are the "gold" standards in this kind of research and in order to compare our results with other researchers we need to ask them again. As you know, offering of genetic testing for breast and ovarian cancer is still relatively new and genetic counselors rely on research like this to plan services. We know that we've asked a lot of you. Thanks again for all your patience.

(1) Affected (0) Unaffected

For AFFECTED Subjects Only:

1. First of all...Before your own diagnosis of cancer (breast or ovarian), Did you believe that you were a member of a family at high risk for breast and ovarian cancer?

(1) Yes (5) No

N1

Researchers are always interested in stress.

Standardized measures of stressful life events have been established with 0 representing no stress and 100 representing the greatest stress. To give you some reference points, here are some examples:

- Change in residence is assigned a stress score of 20
- Pregnancy is 40
- Death of a close family member is 63
- Death of a spouse is 100

Keeping in mind the ratings I just mentioned:

2. How would you rate the stress of being a member of a family at increased risk of breast and ovarian cancer? N2

Being a member of a high risk family _____

3.

<u>UNAFFECTED:</u>	<u>AFFECTED:</u>
Hypothetically....	Thinking about when you were first diagnosed with cancer (breast or ovarian)...

How would you rate the stress of being diagnosed with cancer?

Diagnosis of cancer _____ N3

4. Now, how would you rate the stress of receiving your test results? [By that , I only am referring to the time at which you actually received your results.]

Stress of receiving results _____ N4

5. When you signed up for the study and gave your blood sample, rate how stressful you thought receiving your test results would be?

Stress you had thought getting your test results WOULD be _____ N5

6. Some women tell us that the whole process of getting results went very smoothly, while others tell us that it was an ordeal. Women have been both pleased and annoyed by the information they received or did not receive, the way results were given - that sort of thing. Using our stress ratings, how would you rate the process you went through to get results?

Process to get results _____ N6

- 6a. What about the process has been stressful? Do you have any suggestions for how the process could be improved? N6a

(more space over) _____

Next, we are interested in any recent events in your family related to cancer and risk for cancer. In the past 6 months...

7. To your knowledge, have any of your family members received genetic test results in the past 6 months? What is their relationship to you? Do you know if a mutation was found? Positive or Negative?
 (1) Yes (5) No (Skip to Next Question)

Total # Received Results: _____

N8t

	Relationship to R:	Positive Mutation Found	Negative No Mutation Found	Don't Know
a.		1	0	-9
b.		1	0	-9
c.		1	0	-9

N8a

N8b

N8c

8. Have any family members declined receiving test results (in the past 6 months)?
 (1) Yes (5) No (Skip to Next Question)

Total # Declined Results: _____

N9t

	Relationship to R:
a.	
b.	
c.	

N9a

N9b

N9c

9. Have any family members received a new diagnosis of cancer (in the past 6 months)?
 (1) Yes (5) No (Skip to Next Question)

Total # New Diagnosis: _____

N10t

	Relationship to R:
a.	
b.	
c.	

N10a

N10b

N10c

10. Have any family members had prophylactic surgery (in the past 6 months)?

(1) Yes (5) No (Skip to Next Question)

Total # Prophylactic Surgery: _____

N11

	Relationship to R:	Prophylactic Procedure:	
a.			N11a
b.			N11b
c.			N11c

11. Have any family members had any other things happen related to cancer or risk of cancer (in the past 6 months)? [such as treatment, surgery, or death?]

(1) Yes (5) No (Skip to Next Question)

Total # Family Members with a Cancer Related Event: _____

N12

	Relationship to R:	Event related to cancer:	
a.			N12a
b.			N12b
c.			N12c

12. Using a 5 point scale where 1=Not at All, 2-Rarely, 3=Sometimes, 4=Often, and 5=A Lot, Could you please tell us how often you talk with the following people in your family? If you have more than one close relative in a category, please answer the question thinking about the relative with whom you talk most frequently. How often do you talk with your _____ ?

		Not at All	Rarely	Sometimes	Often	A Lot	Not Applicable	
a.	Spouse	1	2	3	4	5	-8	N28a
b.	Daughter	1	2	3	4	5	-8	N28b
c.	Son	1	2	3	4	5	-8	N28c
d.	Mother	1	2	3	4	5	-8	N28d
e.	Grandmother	1	2	3	4	5	-8	N28e
f.	Sister	1	2	3	4	5	-8	N28f
g.	Aunt	1	2	3	4	5	-8	N28g
h.	Cousin	1	2	3	4	5	-8	N28h

13. Using the same scale, How often do you talk with each of these same people when something important and/or difficult happens in your life?

		Not at All	Rarely	Sometimes	Often	A Lot	Not Applicable	
a.	Spouse	1	2	3	4	5	-8	N29a
b.	Daughter	1	2	3	4	5	-8	N29b
c.	Son	1	2	3	4	5	-8	N29c
d.	Mother	1	2	3	4	5	-8	N29d
e.	Grandmother	1	2	3	4	5	-8	N29e
f.	Sister	1	2	3	4	5	-8	N29f
g.	Aunt	1	2	3	4	5	-8	N29g
h.	Cousin	1	2	3	4	5	-8	N29h

14. Before you actually got your results, How often did you discuss getting genetic testing for breast and ovarian cancer with these family members?

		Not at All	Rarely	Sometimes	Often	A Lot	Not Applicable	
a.	Spouse	1	2	3	4	5	-8	N30a
b.	Daughter	1	2	3	4	5	-8	N30b
c.	Son	1	2	3	4	5	-8	N30c
d.	Mother	1	2	3	4	5	-8	N30d
e.	Grandmother	1	2	3	4	5	-8	N30e
f.	Sister	1	2	3	4	5	-8	N30f
g.	Aunt	1	2	3	4	5	-8	N30g
h.	Cousin	1	2	3	4	5	-8	N30h

15. In the last six months since you received your genetic test results, How often have you discussed the results with each of them?

		Not at All	Rarely	Sometimes	Often	A Lot	Not Applicable	
a.	Spouse	1	2	3	4	5	-8	N31a
b.	Daughter	1	2	3	4	5	-8	N31b
c.	Son	1	2	3	4	5	-8	N31c
d.	Mother	1	2	3	4	5	-8	N31d

		Not at All	Rarely	Sometimes	Often	A Lot	Not Applicable	
e.	Grandmother	1	2	3	4	5	-8	N31e
f.	Sister	1	2	3	4	5	-8	N31f
g.	Aunt	1	2	3	4	5	-8	N31g
h.	Cousin	1	2	3	4	5	-8	N31h

16. Overall, to what extent do your family members talk about themselves as being a family at high risk for breast or ovarian cancer? N32

Not at All	Rarely	Sometimes	Often	A Lot
1	2	3	4	5

Related Comments: _____

17. When you catch-up on what's going on in your family, to what extent are people's experiences with breast or ovarian cancer a topic of conversation? N33

Not at All	Rarely	Sometimes	Often	A Lot
1	2	3	4	5

Related Comments: _____

18. In your family, to what extent do you agree on how to manage risk for breast or ovarian cancer? N34

Not at All	Rarely	Sometimes	Often	A Lot
1	2	3	4	5

Can you give me some examples of ways this comes up? _____

Have there been any disagreements about managing risk for cancer in your family? Can you tell me about that? _____

For those receiving uninformative results (No BRCA1 and BRCA2 Alterations Found AND No one in their family has a BRCA1 or BRCA2 alteration even though there is a family history of breast cancer) :

19. Even though no alteration was found for BRCA1 and BRCA2, Do you believe there is a possibility that you have another altered gene conveying an increased risk for breast and ovarian cancer?

(1) Yes (5) No N13

20. If it becomes available, do you intend to get testing for any additional genes related to risk of breast and ovarian cancer?

(1) Yes (5) No (3) Unsure N14

Now I want to ask you about the impact receiving results had on you. I'm going to ask you to rate the effect that getting your genetic results has had on different areas in your life. Using a scale of 1-5, 1=Very Negative Effect, 2=Somewhat Negative Effect, 3=No Effect, 4=Somewhat Positive Effect, and 5=Very Positive Effect...

21. On the whole, what effect has testing had on your life?

Very Negative Effect	Somewhat Negative Effect	No Effect	Somewhat Positive Effect	Very Positive Effect
1	2	3	4	5

N15

22. Think about your everyday family life. What effect would you say getting the genetic test results has had?

Very Negative Effect	Somewhat Negative Effect	No Effect	Somewhat Positive Effect	Very Positive Effect
1	2	3	4	5

N16

23. What effect has getting your results had on your work in and outside of the home?

Very Negative Effect	Somewhat Negative Effect	No Effect	Somewhat Positive Effect	Very Positive Effect
1	2	3	4	5

N17

24. What effect has getting your results had on your concerns for your child's/children's future?

Very Negative Effect	Somewhat Negative Effect	No Effect	Somewhat Positive Effect	Very Positive Effect
1	2	3	4	5

N19

25. Has getting these results changed the likelihood that you will have (more) children?

No/Fewer Children	No Change	More Children
1	2	3

N22

26. How has it affected your anxiety about the future?

Less Anxiety	No Change	More Anxiety
1	2	3

N18

27. Are there any OTHER areas that testing has affected?

N20

(1) Yes (5) No

27a. Please List Other Areas Affected by Genetic testing:

N20a

(more space over) _____

Now using a different scale of 1-5, 1=Not at All, 2=A Little, 3=Some, 4=Quite a Bit, and 5=Very Much...

28. How much has getting test results changed your health care decision(s)?

Not At All	A Little	Some	Quite a Bit	Very Much
1	2	3	4	5

N21

29. In general, how much has getting genetic results changed your life?

Not At All	A Little	Some	Quite a Bit	Very Much
1	2	3	4	5

N23

Symptoms of Strain Section

I'm going to be reading you some Symptoms Of Strain that people sometimes have. Please listen to each one carefully and tell me the answer which best reflects how much that symptom has BOTHERED you during the **PAST THREE MONTHS**. Please use the following scale: 1=Not at all, 2=A little, 3=Quite a bit, and 4=Extremely.

		<i>Not at all</i>	<i>A little</i>	<i>Quite a bit</i>	<i>Extremely</i>
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	1	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

K1.

K2.

K3.

K4.

K5.

K6.

K7.

K8.

K9.

K10.

		<i>Not at all</i>	<i>A little</i>	<i>Quite a bit</i>	<i>Extremely</i>	
11.	Feeling low in energy--slowed 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.

K26. To what extent are these current symptoms a result of getting genetic testing?

Not At All	A Little	Some	Quite a Bit	Very Much
1	2	3	4	5

K26

The following questions are about any counseling or psychotherapy you have received in the past, either related to cancer issues or other personal issues.

30. Have you ever seen any kind of counselor, therapist, psychologist, psychiatrist, or any other person like that for personal or emotional problems? (ASK the following probes as necessary: What type of person did you see? Why did you go? Have you ever seen someone for cancer issues? For dealing with Genetic Testing?)

Outpatient psychiatric or psychological treatment or counseling in the past 12 months:

- Exclude Educational Sessions with a Genetic Counselor
- Include treatment in outpatient and day hospital settings
- guidance or vocational counseling = No
- Axis I-type symptoms, even if not diagnosed = 3
- bereavement counseling = 4
- didactic analysis or equivalent ONLY for training/education = 8
- Family therapy ONLY to help a family member (subject did not discuss his/her own problems) = 8

Code all reasons that apply Next Page

CODE ALL REASONS THAT APPLY:

- a NO (Skip to Question N25) N24a
- b YES - Depression N24b
- c YES - Other Psychiatric (Axis I) N24c
- d YES - Interpersonal, Behavioral, Stress, Family, Developmental, etc. N24d
- e YES - Cancer Issues (diagnosis) N24e
- f YES - Genetic Testing Issues N24f
- g YES - Other (Specify Next page) _____ N24g

Specify treatment(s) and problem(s) _____

31. Are you currently seeing any kind of counselor, therapist, psychologist, psychiatrist, or any other person like that for personal or emotional problems? (ASK the following probes as necessary: What type of person are you seeing? Why are you going? Are you seeing someone for cancer issues? For dealing with Genetic Testing?)

Outpatient psychiatric or psychological treatment or counseling in the past 12 months:

- Exclude Educational Sessions with a Genetic Counselor
- Include treatment in outpatient and day hospital settings
- guidance or vocational counseling = No
- Axis I-type symptoms, even if not diagnosed = 3
- bereavement counseling = 4
- didactic analysis or equivalent ONLY for training/education = 8
- Family therapy ONLY to help a family member (subject did not discuss his/her own problems) = 8

CODE ALL REASONS THAT APPLY:

- a NO (Skip to Question N26) N25a
- b YES - Depression N25b
- c YES - Other Psychiatric (Axis I) N25c
- d YES - Interpersonal, Behavioral, Stress, Family, Developmental, etc. N25d
- e YES - Cancer Issues (diagnosis) N25e
- f YES - Genetic Testing Issues N25f
- g YES - Other (Specify) _____ N25g

Specify treatment(s) and problem(s) _____

32. Have you ever taken medication for emotional distress, depression, or anxiety?

(1) Yes (Record Meds below) (5) No (Skip to Score Hopkins)

N26

33. What medication(s) did you take? How long did you take this medication? Are you still taking this medication? Were the reasons for starting this medication related to your cancer or your risk for cancer? Were the reasons for starting this medication related to your genetic testing or receiving genetic test results?

Medications for emotional distress, depression, or anxiety:

- Include St. John's Wart
- Exclude Hormonal Treatment and other herbs

	Medication:	Code:	Duration (Months)	Currently Taking?	Related to Cancer ?	Related to Genetic Testing?	
a.				(1) <input type="checkbox"/> Yes (5) <input type="checkbox"/> No	(1) <input type="checkbox"/> Yes (5) <input type="checkbox"/> No	(1) <input type="checkbox"/> Yes (5) <input type="checkbox"/> No	N27a
b.				(1) <input type="checkbox"/> Yes (5) <input type="checkbox"/> No	(1) <input type="checkbox"/> Yes (5) <input type="checkbox"/> No	(1) <input type="checkbox"/> Yes (5) <input type="checkbox"/> No	N27b
c.				(1) <input type="checkbox"/> Yes (5) <input type="checkbox"/> No	(1) <input type="checkbox"/> Yes (5) <input type="checkbox"/> No	(1) <input type="checkbox"/> Yes (5) <input type="checkbox"/> No	N27c
d.				(1) <input type="checkbox"/> Yes (5) <input type="checkbox"/> No	(1) <input type="checkbox"/> Yes (5) <input type="checkbox"/> No	(1) <input type="checkbox"/> Yes (5) <input type="checkbox"/> No	N27d
e.				(1) <input type="checkbox"/> Yes (5) <input type="checkbox"/> No	(1) <input type="checkbox"/> Yes (5) <input type="checkbox"/> No	(1) <input type="checkbox"/> Yes (5) <input type="checkbox"/> No	N27e
f.				(1) <input type="checkbox"/> Yes (5) <input type="checkbox"/> No	(1) <input type="checkbox"/> Yes (5) <input type="checkbox"/> No	(1) <input type="checkbox"/> Yes (5) <input type="checkbox"/> No	N27f

INTERVIEWER: Go back to Score Hopkins-25 (Symptoms of Strain Section, p. 8) by adding up the numbered answers for K1-K25:

Score _____ If score = "44 or more," Complete SCID modules **SCID Completed**
 If score = "43 or less," Skip SCID modules

WHEN FINISHED WITH INTERVIEW BE SURE TO TELL SUBJECT:

- We have a short questionnaire that we will mail in about a week with some different questions.
- We'd like to contact everyone (one last time) in about 6 months, if that is okay.
- Check Address
- Thank subject.

CSID -

INTERVIEWER _____

SCID Modules--Post-Results.2
6 Month Follow-Up Interview

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 asses **Current Dysthymia**, A38-A42.

Anxiety Disorders.

We assess **Current Generalized Anxiety Disorder**, F31-F35.

We then assess **Current Mixed Anxiety Disorder**, J5-J8.

Edited: _____

IN THIS SECTION, MAJOR DEPRESSIVE, DYSTHYMIC DISORDER, MOOD DISORDER DUE TO A GENERAL MEDICAL CONDITION, AND SUBSTANCE-INDUCED MOOD DISORDER ARE EVALUATED.

CURRENT MAJOR DEPRESSIVE EPISODE

MDE CRITERIA

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

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.

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?

(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.

? 1 2 3 A1

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

(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)

? 1 2 3 A2

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

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

? = inadequate information

1 = absent or false

2 = subthreshold

3 = threshold or true

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)...

<p>..did you lose or gain any weight? (How much?) (Were you trying to lose weight?)</p>	<p>(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:</p>	?	1	2	3	A3
<p>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?)</p>	<p>_____ weight loss or decreased appetite _____ weight gain or increased appetite</p>					A4
						A5
<p>..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? Was that nearly every night?)</p>	<p>(4) insomnia or hypersomnia nearly every day</p>	?	1	2	3	A6
	<p>Check if: _____ insomnia _____ hypersomnia</p>					A7
						A8
<p>..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?)</p>	<p>(5) psychomotor agitation or retardation nearly every day (observable by others, not merely subjective feelings of restlessness or being slowed down)</p>	?	1	2	3	A9
	<p>NOTE: CONSIDER BEHAVIOR DURING THE INTERVIEW Check if:</p>					A10
<p>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?)</p>	<p>_____ psychomotor retardation _____ psychomotor agitation</p>					A11
<p>..what was your energy like? (Tired all the time? Nearly every day?)</p>	<p>(6) fatigue or loss of energy nearly every day</p>	?	1	2	3	A12

? = inadequate information

1 = absent or false

2 = subthreshold

3 = threshold or true

SCID (DSM-IV)	Current MDE (WHS 5/98)	Mood Episodes			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: _____ worthless _____ inappropriate guilt	?	1	2	3	A13
..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?)	(8) diminished ability to think or concentrate, or indecisiveness, nearly every day (either by subjective account or as observed by others) check if: _____ diminished ability to think _____ indecisiveness	?	1	2	3	A16 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 NOTE: CODE "1" FOR SELF-MUTILATION W/O SUICIDAL INTENT Check if: _____ thoughts of own death _____ suicidal ideation _____ specific plan _____ suicide attempt	?	1	2	3	A19 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		1		3	A24
			GO TO *CURRENT DYSTHYMIC DISORDER* A.38			

SCID-I (DSM-IV)

Current MDE

(WHS 5/98)

Mood Episodes

A.4

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
***CURRENT
DYSTHYMIC
DISORDER***
A.38

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

? 1 3 A26

DUE TO SUB-
STANCE USE
OR GMC.
GO TO
***CURRENT
DYSTHYMIC
DISORDER***
A.38

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, 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)

PRIMARY
MOOD
EPISODE

CONTINUE
BELOW

? = inadequate information

1 = absent or false

2 = subthreshold

3 = threshold or true

(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.

1	3	A27
SIMPLE BEREAVE- MENT	NOT SIMPLE BEREAVE- MENT	
GO TO *CURRENT DYSTHYMIC DISORDER*	CONTINUE BELOW	
A.38		

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

1	3	A28
GO TO *CURRENT DYSTHYMIC DISORDER*	CURRENT MAJOR DEPRESSIVE EPISODE	
A.38		

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)

_____ A29

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

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.

***DYSTHYMIC DISORDER*
(CURRENT ONLY)**

DYSTHYMIC DISORDER CRITERIA

-> 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?)

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
***CURRENT
GENERALIZED
ANXIETY
DISORDER***
F.31

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?)

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

Mo/Yr: ____ / ____ Age: ____

-> FOR A PAST MAJOR DEPRESSIVE EPISODE DURING THE PAST TWO YEARS: Let's review when you first had most of the symptoms of (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?

FIRST MET CRITERIA FOR 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: ____

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?)

During these periods of (OWN EQUIVALENT FOR CHRONIC DEPRESSION), do you often...

B. Presence, while depressed, of two (or more) of the following:

...lose you appetite?(What about overeating?)

(1) poor appetite 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 or feel tired a lot?

(3) low energy or fatigue

? 1 2 3 A166

...feel down on yourself? (Feel worthless, or a failure?)

(4) low self-esteem

? 1 2 3 A167

... have trouble concentrating or making decisions?

(5) poor concentration or difficulty making decisions

? 1 2 3 A168

...feel hopeless?

(6) feelings of hopelessness

? 1 2 3 A169

AT LEAST TWO "B" SYMPTOMS CODED "3"

? 1 2 3 A170

GO TO
 *CURRENT
 GENERALIZED
 ANXIETY
 DISORDER*
 F.31

What is the longest period of time, during this period of long-lasting depression, that you felt ok?(NO DYSTHYMIC SYMPTOMS)

C. During the two year period (one-year for children or adolescents) of the disturbance, the person has never been without the symptoms in A and B for more than two months at a time.

? 1 3 A171

GO TO
 *CURRENT
 GENERALIZED
 ANXIETY
 DISORDER*
 F.31

NOTE: CODE "1" IF NORMAL MOOD FOR AT LEAST TWO MONTHS AT A TIME

SCID-I (DSM-IV)

Dysthymic Disorder

(WHS 5/98)

Mood Episodes

A.40

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

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.

? 1 2 3

A172

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.

GO TO *CURRENT GENERALIZED ANXIETY DISORDER* F.31

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.

1 3

A174

GO TO *CURRENT GENERALIZED ANXIETY DISORDER* F.31

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

? 1 3 A175

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

GO TO *CURRENT GENERALIZED ANXIETY DISORDER* F. 31 NOT SUPER-IMPOSED | CON-TINUE

? = inadequate information

1 = absent or false

2 = subthreshold

3 = threshold or true

SCID-I (DSM-IV) Dysthymic Disorder (WHS 5/98) Mood Episodes A.41

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 using any street drugs?

G. 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 *SUBSTANCE/ GMC* A.43 RETURN HERE AND MAKE RATING OF "1" OR "3"

Etiological general medical conditions include: degenerative neurological illnesses (e.g., 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 known or unknown substances (e.g., steroids).

? 1 3 A176 |
 |
 DUE TO
 SUBSTANCE
 USE OR GMC

|
 GO TO
 *CURRENT
 GENERALIZED
 ANXIETY
 DISORDER*
 F. 31

PRIMARY
 MOOD
 DISORDER
 |
 CONTINUE

IF UNCLEAR: How much do your depressed feelings interfere with your life?

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

? 1 3 A177
 |
 GO TO
 *CURRENT GENER-
 ALIZED ANXIETY
 DISORDER*, F.31

DYSTHYMIC DISORDER
 CRITERIA A, B, C, D, E, F,
 AND H ARE CODED "3"

1 3 A178
 |
 DYSTHYMIC
 DISORDER

IF DYSTHYMIC DISORDER
 Indicate specifier:
 1- Early Onset: onset before age 21
 2- Late Onset: onset age 21 or older

Specifier: _____ A179

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

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 ***GENERALIZED ANXIETY DISORDER*, F.31** A187

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] ? 1 2 3 A188

(2) prominent anxiety, panic attacks, obsession or compulsions [FOR ANXIETY] ? 1 3 A189

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

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).

? 1 2 3 A190 GO TO *SUB- STANCE INDUCED* A.45
--

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?

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 CONDITION.

? = inadequate information

1 = absent or false

2 = subthreshold

3 = threshold or true

3) THE MOOD/ANXIETY SYMPTOMS 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

?	1	2	3	A191
	GO TO			
	*SUB-			
	STANCE-			
	INDUCED*			
	A.45			

D. The disturbance does not occur exclusively during the course of Delirium.

	1		3	A192
	DELIRIUM		MOOD/	
	DUE TO A		ANXIETY	
	GMC		DISORDER	
			DUE TO A	
			GMC	

SUBSTANCE -INDUCED MOOD/ANXIETY DISORDER

SUBSTANCE-INDUCED MOOD/ANXIETY DISORDER CRITERIA

EPISODE BEING EVALUATED:	
Current MDE	A.1
Dysthymia	A.38

IF SYMPTOMS NOT TEMPORALLY ASSOCIATED WITH SUBSTANCE, CHECK HERE _____ AND RETURN TO EPISODE BEING EVALUATED.

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.

? 1 2 3 A196

NOT SUBSTANCE INDUCED RETURN TO EPISODE BEING EVALUATED

Do you think your (MOOD/ ANXIETY SXS) are in any way related to your (SUBSTANCE USE)?

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:

? 1 2 3 A197

NOT SUBSTANCE INDUCED RETURN TO EPISODE BEING EVALUATED

IF YES: Tell me how.

ASK ANY OF THE FOLLOWING QUESTIONS AS NEEDED TO RULE OUT A NON-SUBSTANCE-INDUCED ETIOLOGY:

IF UNKNOWN: Which came first, the (SUBSTANCE USE) or the (MOOD/ANXIETY SYMPTOMS)?

1) the mood/anxiety symptoms precede the onset of the Substance Abuse or Dependence

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)

? = inadequate information

1 = absent or false

2 = subthreshold

3 = threshold or true

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?

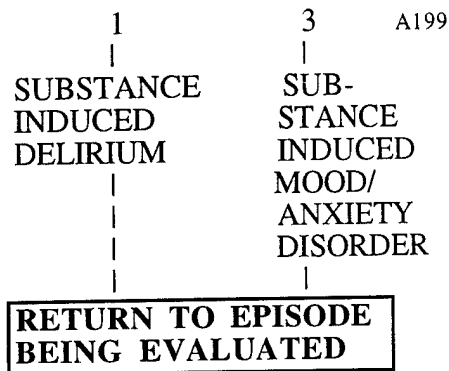
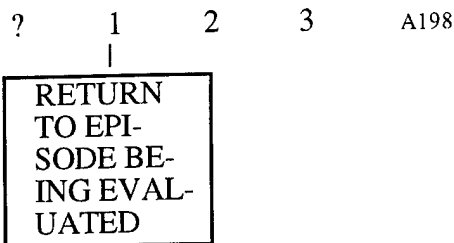
IF UNKNOWN: How much did (MOOD/ANXIETY SYMPTOMS) interfere with your life?

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.



***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])

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?

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

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)

B. The person finds it difficult to control the worry

F(2). Does not occur exclusively during the course of a Mood Disorder, Psychotic Disorder, or a Pervasive Developmental Disorder

? 1 2 3 F135
|
GO TO
***MIXED ANXIETY DISORDER,* J.5**

? 1 2 3 F136
|
GO TO
***MIXED ANXIETY DISORDER,* J.5**

? 1 2 3 F137
|
GO TO
***MIXED ANXIETY DISORDER,* J.5**

? = inadequate information

1 = absent or false

2 = subthreshold

3 = threshold or true

Now I am going to ask you some questions about other symptoms that often go along with being nervous.

C. The anxiety and worry are associated with at least three of the following such symptoms (with at least some symptoms present for more days than not for the past six months) :

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) restlessness or feeling keyed up or on 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) difficulty concentrating or mind going blank

? 1 2 3 F140

... are you often irritable?

(4) irritability

? 1 2 3 F141

...are your muscles often tense?

(5) muscle tension

? 1 2 3 F142

...do you often have trouble falling or staying asleep?

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

? 1 2 3 F143

AT LEAST THREE "C" SXS ARE CODED "3"

1 3 F144

GO TO
*MIXED
ANXIETY
DISORDER*
J.5

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 3 F145
|
**GO TO
*MIXED
ANXIETY
DISORDER*
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 anxiety, 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"

? 1
| |
DUE TO SUB-
STANCE USE
OR A GMC

GO TO
*MIXED
ANXIETY
DISOR-
DER,* J.5

1
|
GO TO
*MIXED
ANXIETY
DISOR-
DER,* J.5

3 F147

PRIMARY
ANXIETY
DISORDER

CONTINUE

3 F148

GENER-
ALIZED
ANXIETY
DISORDER

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.

? = inadequate information

1 = absent or false

2 = subthreshold

3 = threshold or true

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.

?	1	2	3	J20
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	3	J21
---	---	---	---	-----

...have you had trouble sleeping?

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

?	1	2	3	J22
---	---	---	---	-----

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

(3) fatigue or low energy

?	1	2	3	J23
---	---	---	---	-----

...have you felt irritable or cranky?

(4) irritability

?	1	2	3	J24
---	---	---	---	-----

...did you worry a lot about things?

(5) worry

?	1	2	3	J25
---	---	---	---	-----

...did you find yourself crying over little things?

(6) easily moved to tears

?	1	2	3	J26
---	---	---	---	-----

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

(7) hypervigilance

?	1	2	3	J27
---	---	---	---	-----

? = inadequate information

1 = absent or false

2 = subthreshold

3 = threshold or true

SCID-I (DSM-IV)

MAD

(WHS 5/98)

...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

J29

...did you feel down on yourself or that you were worthless?

(10) low self-esteem or feelings of worthlessness

? 1 2 3

J30

AT LEAST FOUR "B"
SYMPTOMS CODED "3"

? 1 3

J31

|
DONE

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

|
|
|
DONE

? = inadequate information

1 = absent or false

2 = subthreshold

3 = threshold or true

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

? 1 3
| |
DUE TO
SUBSTANCE
USE OR A
GMC.
DONE

J33

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."

PRIMARY
ANXIETY
DISORDER

Etiological general medical conditions include: hyper- and hypo-thyroidism, hypoglycemia, hyper-parathyroidism, pheochromocytoma, congestive heart failure, arrhythmias, 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.

CONTI-
NUE

E. All of the following:

? 1 3

J34

(1) Has never met criteria for Major Depressive Disorder, Dysthymic disorder, Panic Disorder, or Generalized Anxiety Disorder.

DONE

(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

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

1

3

J35

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)

J36

**DONE WITH
SCID**

? = inadequate information

1 = absent or false

2 = subthreshold

3 = threshold or true