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GRANT NUMBER DAMD17-96-1-6191

TITLE: Delays and Refusal in Treatment for Breast Cancer Among
Native American and Hispanic Women with Breast Cancer

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REPORT DATE: August 1998

TYPE OF REPORT: Annual

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

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REPORT DOCUMENTATION PAGE

Form Approved
OMB No. 0704-0188

Public reporting burden for this collection of information is estimated to average 1 hour per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to Washington Headquarters Services, Directorate for Information Operations and Reports, 1215 Jefferson Davis Highway, Suite 1204, Arlington, VA 22202-4302, and to the Office of Management and Budget, Paperwork Reduction Project (0704-0188), Washington, DC 20503.

1. AGENCY USE ONLY (Leave blank)		2. REPORT DATE August 1998	3. REPORT TYPE AND DATES COVERED Annual (1 Aug 97 - 31 Jul 98)	
4. TITLE AND SUBTITLE Delays and Refusals in Treatment for Breast Cancer Among Native American and Hispanic Women with Breast Cancer			5. FUNDING NUMBERS DAMD17-96-1-6191	
6. AUTHOR(S) Elba L. Saavedra Elias Duryea				
7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES) University of New Mexico Albuquerque, New Mexico 87131-5141			8. PERFORMING ORGANIZATION REPORT NUMBER	
9. SPONSORING/MONITORING AGENCY NAME(S) AND ADDRESS(ES) Commander U.S. Army Medical Research and Materiel Command Fort Detrick, Frederick, 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	
13. ABSTRACT (Maximum 200) Purpose: The aim of this study is to describe the factors associated with delays in breast cancer treatment among Hispanic, Native American and non-Hispanic white women. Scope: The study will enroll a total of 70 participants, 35 patients and 35 caregivers identified by the patient. This ethnographic study will gather qualitative data on the psychosocial, cultural, attitudinal, spiritual and demographic variables associated with delays in breast cancer treatment. The focus of the semi-structured interview is to encourage the women in story-telling about their breast cancer experiences. Interviews will be conducted for a minimum of two sessions. The study collaborates with representatives from the New Mexico B&CC Program, regional community health advisors, The Gathering of Cancer Support, the Navajo B&CC, The Navajo Nation, People Living Through Cancer, and the New Mexico Tumor Registry. Summary: Accomplishments for this project period include; an extensive review and identification of potential participants from the B&CC Program breast cancer database, finalization of discussion guides for the study, establishment of study protocols for identification and contacting participants, increased community support and involvement in the study design and implementation, continued support and input from the breast cancer survivor community, and increased input from community health advisors.				
14. SUBJECT TERMS Breast Cancer			15. NUMBER OF PAGES 78	
			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	

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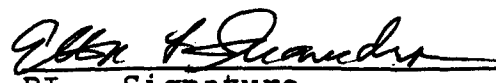
 10/31/98
PI - Signature Date

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5. Introduction

Study Significance

In contrast to their relatively low incidence rates for breast cancer, both American Indian and Hispanic women in New Mexico who develop the disease show poorer survival rates than non-Hispanic whites^{1,2}. Part of this difference in survival rates can be attributed to stage of disease at presentation for medical care. Historically, Hispanic and American Indian women have presented with more advanced (later stage) disease at the time of diagnosis when compared to non-Hispanic white women.

A recent New Mexico study showed, however, that not all this survival difference can be attributed to stage of disease. After controlling for differences in stage of disease at the time of presentation for care, differences in survival among ethnic groups were still found². Other possible explanations for these differences include factors related to the patient's health and genetics, factors related to the aggressiveness of the tumor, and factors related to the treatment itself, including choice of treatment modality and compliance with treatment. Compliance with treatment has been anecdotally cited among physicians in New Mexico as a significant factor among Native American women with breast cancer. Geographic isolation, transportation problems, and cultural beliefs have been proposed as possible explanations for increased non-compliance or delays in treatment.

A previous retrospective analysis examining timeliness in the evaluation of breast cancer reported delays in breast cancer treatment. That study of 108 breast cancers cases diagnosed through the CDC funded Breast and Cervical Cancer Detection Program (B&CC) for the period 1991-1994, identified a sub-set (15 percent) of women with delays in treatment³.

In that same study, data were gathered on distance traveled to treatment site(s). Diverse patterns emerged in different counties. Several counties had no women who traveled 25 miles or greater to their treatment site. Several other counties (particularly McKinley and San Juan) had a large subset of women traveling long distances for their treatment ³.

The poor survival rates among Native American and Hispanic women with breast cancer, the established relationship between timely diagnosis and survival, and the preliminary findings noted above, all lend importance to the current study.

Subject of the Study

A substantial body of literature supports the critical importance of early diagnosis and treatment for improving prognosis in breast cancer. Despite the widely acknowledged importance of timeliness in diagnosis and treatment, little is known about delays occurring during treatment. Nearly all of the existing literature focuses on the screening and diagnostic phases of breast cancer care. If delays exist during treatment, the benefits of early detection achieved through widespread mammography screening can be lost. Previous studies have documented the progression of disease during delays in diagnosis and treatment ^{4,5}. Characterization of those delays will identify explanatory factors and suggest interventions to improve outcomes.

Purpose

The purpose of this study is to understand and describe the factors associated with delays in breast cancer treatment among a group of Native American (Pueblo and Navajo), Hispanic and non-Hispanic white women who have delayed treatment for breast cancer.

Scope of the Research

As discussed in the original proposal, the design of this study will use an ethnographic approach comprised of in-depth interviews. These in-depth

interviews will be conducted in a manner that permits a wide range of information to be elicited on the psychosocial, cultural, attitudinal, spiritual, and demographic factors associated with delays and refusals in breast cancer treatment. Perceptions of an illness such as breast cancer are influenced in part by the characteristic ways in which medical conditions and corresponding situations are framed and interpreted. The ethnographic approach allows us to understand actions in the context the shared framework of meanings that constitutes "culture"⁶.

Researchers are becoming increasingly aware of the role that family plays in illness and health. The patterns of social relationships among family members can either increase an individual's risk and vulnerability to disease or conversely provide a buffer that strengthens the resilience of vulnerable persons. Interviews will also be conducted with an identified family caregiver (spouse, daughter, sister). Perceptions of cancer, the impact of treatment decisions on the family, and how they see themselves providing support or assistance will be elicited.

Methods

Data Gathering

The study is currently enrolling a total of 70 participants, 35 patients and 35 family members or other caregivers identified by the patient. Qualitative data is being gathered through tape recorded semi-structured interviews of both the patient and a family member or care-giver. Interviews will be conducted for a minimum of two sessions, as needed for completion of data collection.

Progress with the data gathering phase is discussed in detail in the next section.

6. Body

Conceptual Framework of Delays in Breast Cancer Care

In the course of the past year, an expanded and more clearly defined conceptual framework has been developed for the factors influencing delays and non-completion with treatment in breast cancer care (Appendix B). The patient's experience with the clinical diagnostic evaluation and treatment can be impacted by three broad classes of mediating variables; those related to the patient, those related to the provider, and those related to the health care system. These variables influence the type of resolution (completion or non-completion of treatment), and therefore ultimately impact outcomes. The relative impact of each of these variables is filtered through the cultural perspective through which a woman views her life experiences.

Culturally Specific Variables Relevant To the Study

Hispanic Women and Cancer

In the past year, a clearer understanding of the cultural components important in this study has been developed and confirmed through continued reviews of the literature and discussion with experts in the field. Saint-Germain and Longman (1993) conducted a study examining attitudes toward breast cancer among 409 Hispanic women over the age of 50 living in Tucson, Arizona. Some of the findings from this study elucidate the differences that exist in cultural definitions of health and illness. For example, health and illness are defined not only through external cues, such as symptoms, but in the ability of the person to carry on with his or her daily activities. "If one can still work then one is not ill". The women in the study also displayed misunderstanding about the contagiousness of cancer. Culturally based concerns about the imbalance of the body resulting from a mastectomy were also stressed by a number of women.

The attitudes displayed by these women about breast cancer treatment showed a distinct focus on the negative aspects of side effects and the impact that it would

have on the family. In contrast, women with a relative who had gone through therapy were not as afraid. This article confirms the importance of examining the experiences of cancer therapy among Hispanic women and their family, as well as culturally based ideas about individual treatment modalities.

In his review of curanderismo (1983), Maduro provides an excellent overview of the basic principle of curanderismo as a holistic approach to health. The concept of well being for some Latinos or Hispanics is based on maintaining harmony between hot and cold, wet and dry. A belief therefore exists that illness will result if these areas are not balanced. Treatment is based on attempt to restore the proper balance of these humors. The personable nature of the practitioner (the curandero or curandera) and the emphasis on the emotions is more in step with the holistic Latino world perspective.

In summary, although there is a dearth of studies on culturally held beliefs related to breast cancer among Hispanic women, some have been identified in the literature. Reported views and importance of beliefs about surgery, the familial experience with cancer, the role of the curandero and prayer in treatment, all were identified as important for some Hispanic women. The investigator has included these factors as items in the patient interview guide (Appendix C).

Native American Women and Cancer

In the AMC Native American Cancer Research Program's video Native American Breast Cancer Survivors: Stories of Our Diagnosis (1996), Native American women discussed their fears and the impact their diagnosis had on them and their loved ones. They repeatedly conveyed the significance of their families, who took active roles in these women's recovery. One older and more traditional Native American woman shared how she had not known what cancer was, until it was translated and explained to her by her family. Another Native American breast cancer survivor echoed the importance of having a social

support system during this time. A Native American physician explained that a woman diagnosed with breast cancer may undergo a delayed reaction to the diagnosis and emphasized the need to have someone accompany the woman to clinic visits (Appendix D).

It is important to keep in mind that communication styles among many Native Americans are different. Also the Indian belief system regarding disease is different than the Western medical disease model. Among some Native Americans illness can be seen as a sign of disharmony in both the physical and spiritual realms. A holistic view of taking care of oneself integrates the spiritual as well as the physical. The use of traditional tribal healing practices needs to be respected as an expression of a culture which has coped in its own way with disease and healing for centuries ¹⁰.

Molina (1997) also discusses the significance of the individual's cultural heritage and experience in their definition of illness and disease. Physicians have a difficult time integrating the concepts of culture and disease. The Western system of medicine trains physicians to diagnose and treat disease as an isolated physiologic phenomenon. For Native Americans, life events often require spiritual interpretation. The Medicine Man or Medicine Woman may at times be called upon to seek the meaning behind an event or illness. An awareness of cultural customs among providers can help them to better frame their approach to the patient's specific cultural influences. When this understanding occurs, the patient's response to the medical treatment can be increased.

Socioeconomic Variables

Lower economic status, poverty and lower educational levels have been associated with advanced stage at diagnosis and poorer survival ¹². These factors may also contribute to ethnic differences in New Mexico. Fewer Native American (27.7%) and Hispanics (27.7%) have higher educational levels than non-Hispanic whites (59.3%). More families were below the poverty level in Native American Indian households (46.0%) and Hispanics (27.8%) than in non-Hispanic white

households (10.8%). In addition, more Native American (64.9%) and Hispanics (28.7%) than non-Hispanic whites (22.5%) reside in rural communities².

Summary

In the past year the investigator has identified cultural components as well as other critical factors important to the conduct of research among Hispanic and Native American populations and cancer, specifically breast cancer. In addition, these components are consistent with the scope of the study and are reflected in the items of the interview (Appendices A-C).

Identification of Patients

Enrollment Criterion

The following criterion was used to enroll women into the study: Any documented variation from the recommended plan of treatment during the first four months due to the patient's actions or decisions. Study participants will continued to be enrolled as charts are reviewed and participant meets the selection criteria.

Sampling

The study utilized a criterion sampling technique, consisting of all cases that meet the criteria of the study, during the time period from July 1991 through January 1997.

Breast Cancer Database Selection of Cases

The study's population includes thirty-five Native American, Hispanic and Non-Hispanic white women diagnosed with breast cancer and thirty-five identified family members/ caregivers. Participants have been identified through the breast cancer database of the Breast and Cervical Cancer (B&CC) Program. The records of 371 patients referred for their recommended first course treatment (surgery, chemotherapy, radiation, hormonal and immunotherapy)

and identified in the B&CC Program and NMTR database were reviewed. All Patients who's records indicated a SEER code of "7" (patient or patient's guardian refused the specific therapy) or "8" (treatment recommended, unknown if administered) were selected as candidates for the study. In the case of surgery, cases that had a code of "10" (indicates the patient had less than a total mastectomy and or just an excisional biopsy) or a code of "00" (no surgical procedure) were also selected for review.

In order to select patients that fit the delay criteria, the investigator, manually reviewed the latest B&CC breast cancer database (matched file with the NMTR, March of 1997). This was necessary to identify patients who delayed treatment, but completed treatment later (these cases would not have codes "7", "8", or "10"). Only by examining the patient records could an assessment of delays be made.

As a result of this process of patient identification, twenty-five patients were identified as candidates for enrollment into the study. The ethnic breakdown for these potential participants is as follows: Native American (14), Hispanic (4) and non-Hispanic Whites (7). These participants reside in various areas of the state of New Mexico (Appendix E).

Completion of Medical Abstract Form

A medical abstract form has been completed on each patient. Study identification numbers were issued to each participant for confidentiality and for proper contact and follow-up (Appendix F).

Contact of Patients

The following protocol will be implemented to establish contact with the participant. A letter explaining the nature of the study will be sent to the follow-up physician noted on the NMTR record for the patient. The physician will be requested to inform the patient of the study or to give permission to contact the patient. After the physician sends a letter to the patient, a follow-up letter from

the investigator will be sent explaining the study. The investigator to obtain enrollment into the study (Appendix G, Ga.) will initiate other telephone, mail, or home visit follow-up.

These procedures will be implemented with the Native American participants pending Navajo IRB approval. The investigator is in the process of meeting with Navajo-speaking community health advisors from the Shiprock and Gallup area to assist in contacting the patients. These two health workers currently conduct many of the follow-up contacts for the B&CC mammography-screening program. They may be familiar with the women who have been identified as potential study participants. The investigator has met with and discussed interviewing of Pueblo women with the director of the Gathering of Cancer Support, Mary Lovato.

The investigator has secured the assistance of the community health educator on staff at one of the B&CC provider clinics in Albuquerque. This outreach worker is Hispanic, bilingual-bicultural, and conducts the clinic follow-up for the mammography-screening program at six B&CC provider clinics serving primarily Hispanic patients. Contacting of Hispanic and non-Hispanic participants is currently in process and expected to be completed end of November 1998. Interviewing of participants will commence in November as patients are contacted.

Identification of Interviewers

The Investigator (primary interviewer) and a Hispanic Spanish-speaking health educator (back-up) will conduct the interviews with the Hispanic women. The investigator will conduct the interviews with the non-Hispanic white women in the study.

Trained Pueblo and Navajo interviewers will interview the Native American women. The interviews will be tape-recorded and later transcribed by someone other than the interviewer who speaks the language. The prepared interview

guide for the semi-structure interviews is intended to guide the participant in providing responses on the subject. The purpose of the in-depth interviews is to obtain the stories as told by the women themselves. The probe questions are included to assist the participant in discussing areas important to the study. The probe questions will be asked only if the participant does not spontaneously address the issue herself. The primary focus of these interviews is to encourage the participants in story -telling about their breast cancer experiences. Story-telling is a natural and comfortable way of communicating for this group of women. This approach generally appeals to all the women in the study, regardless of ethnicity. It emphasizes sharing their experiences with this disease in their own words, without the structure imposed by survey type interviews.

In cases where the participant is primarily Navajo or Pueblo speaking, the questions will be translated by the interviewer orally. The Navajo language is a primarily oral language therefore the interview will not be translated before hand. The investigator has consulted with Dr. Clo Mingo, an experienced qualitative researcher in New Mexico, on this matter. Dr. Mingo recently completed twenty-eight focus groups with Hispanic and Navajo women to assess ethnic variations in attitudes and experiences regarding hysterectomy and hormone replacement therapy. Dr. Mingo suggested the use of local Navajo interviewers and transcribers for the current study.

This study will utilize two Navajo-speaking interviewers and one Pueblo interviewer. In the case of the Navajo-speaking interviewers, one interviewer will be primarily responsible for the interviews. The other will serve as a back up. The investigator and the interviewers will review questions to establish consistency in the translation of unfamiliar medical terminology.

Transcription of the Interviews- Navajo or Pueblo Languages

The interviews will be tape recorded and later transcribed. The investigator has identified Navajo speaking transcribers.

A written Spanish interview guide will be produced. Two Spanish- speaking translators with experience translating and transcribing interviews in Dr. Mingo's focus groups have been identified. The Spanish interview guide will subsequently be back-translated into English.

Review of the Interview Guide

The investigator has reviewed questionnaires published in the literature examining similar variables among patients with breast cancer. The key subject areas derived from the literature were cross checked with the items in the guides. Drs. C. Woods (faculty qualitative methods specialist), C. Herman (physician/ women's health researcher), and E. Duryea (faculty research advisor) reviewed the interview guides. Five Hispanic breast cancer survivors from the People Living Through Cancer also reviewed both the patient and family interview guides. The interview guide was also sent to Dr. Linda Burhanstipanov, director of the Native American Cancer Initiatives, for review of cultural sensitivity and appropriateness to Native American cancer beliefs. In addition, Dr. Jennie R. Joe director of the Native American Research and Training Center in Arizona, who is Navajo and a breast cancer survivor, has also agreed to review the patient and family guide. The interview guides have been revised in accordance with these recommendations (Appendix H).

Field-testing of the Interview Guide

The interview guides are scheduled for field testing among representatives from the three communities being studied for the third week of November. In each case, a participant and a family member has been identified. Once this process is completed, the guide will be modified and finalized. In the case of the Native American participants, the investigator is awaiting the Navajo Nation's IRB approval before field testing the interview guide.

Learning from Community Health Workers

The study investigator has visited with community health workers working with women similar to the study participants, and has gained an appreciation of the many barriers faced by these women. Some of those workers shared the difficulties involved in simply finding the women due to the remoteness of the area. In addition the workers reinforced the understanding of the importance of transportation as a significant barrier for low-income rural women. Visiting the clinic sites in these and other areas, talking to the various outreach workers who's job it is to bring women in for follow-up, has provided rich insight that reinforces the importance of this study and validates the qualitative approach.

New Mexico Breast and Cervical Cancer Detection and Control Program

The investigator continues to meet with and strengthen ties with the New Mexico Breast and Cervical Cancer Program (B&CC) Program. The Program continues to be supportive and enthusiastic about the future findings of this study.

Navajo Breast and Cervical Cancer Project

The investigator has developed ongoing meetings with the newly formed Navajo Breast and Cervical Cancer Project. The Navajo Breast and Cervical Cancer Project has been transferred into the research component of the Navajo Division of Health. The investigator has met with the director Camelita Davis and advises her of the progress of the project. Although developing these relationships has been a labor-intensive process, the investigator strongly believes that it is crucial to building a working partnership with the Navajo Nation Breast and Cervical Cancer Project and the Navajo Nation.

Navajo Nation Health Research Review Board

As reported in the first year's report, significant developments have also occurred between the Navajo Nation and the Navajo Area Indian Health Service, regarding the transition of the functions of the IHS institutional review board to the Navajo Nation. As a result, the NNHRRB is now the institutional review

board for the Navajo Nation. The investigator is currently scheduled to present the study to the NNHRRB on December 17th.

The investigator will be presenting the study to the community Chapter House in Churchrock, New Mexico at the Chapter House's planning meeting. Approval and a support letter from the Chapter House is required for overall NNHRRB approval (Appendix I). It is important to note that research in Indian communities must be conducted according to the time schedule of the community itself. Due to the cross-cultural nature of the research, and the sensitivity about research in their communities, research can take considerably longer.

Summary

In summary, a strong foundation for the implementation of the study has been laid. Study methods have been clarified further, the population has been identified, and the discussion guide largely finalized. Perhaps most significantly, a strong network of community lay advisors, breast cancer survivors, tribal health workers has been developed, without which the smooth implementation of the study would be impossible.

Specific Concerns in Previous Annual Report

The investigator has addressed the concerns mentioned in the first year's summary review comments regarding Tasks 4a, 7, 8, 9. In addition, concerns regarding identification of cultural components, the identification of patients and the conduct of the interviews, have also been addressed in this report.

Unexpected Delays and Proposed Adjustments

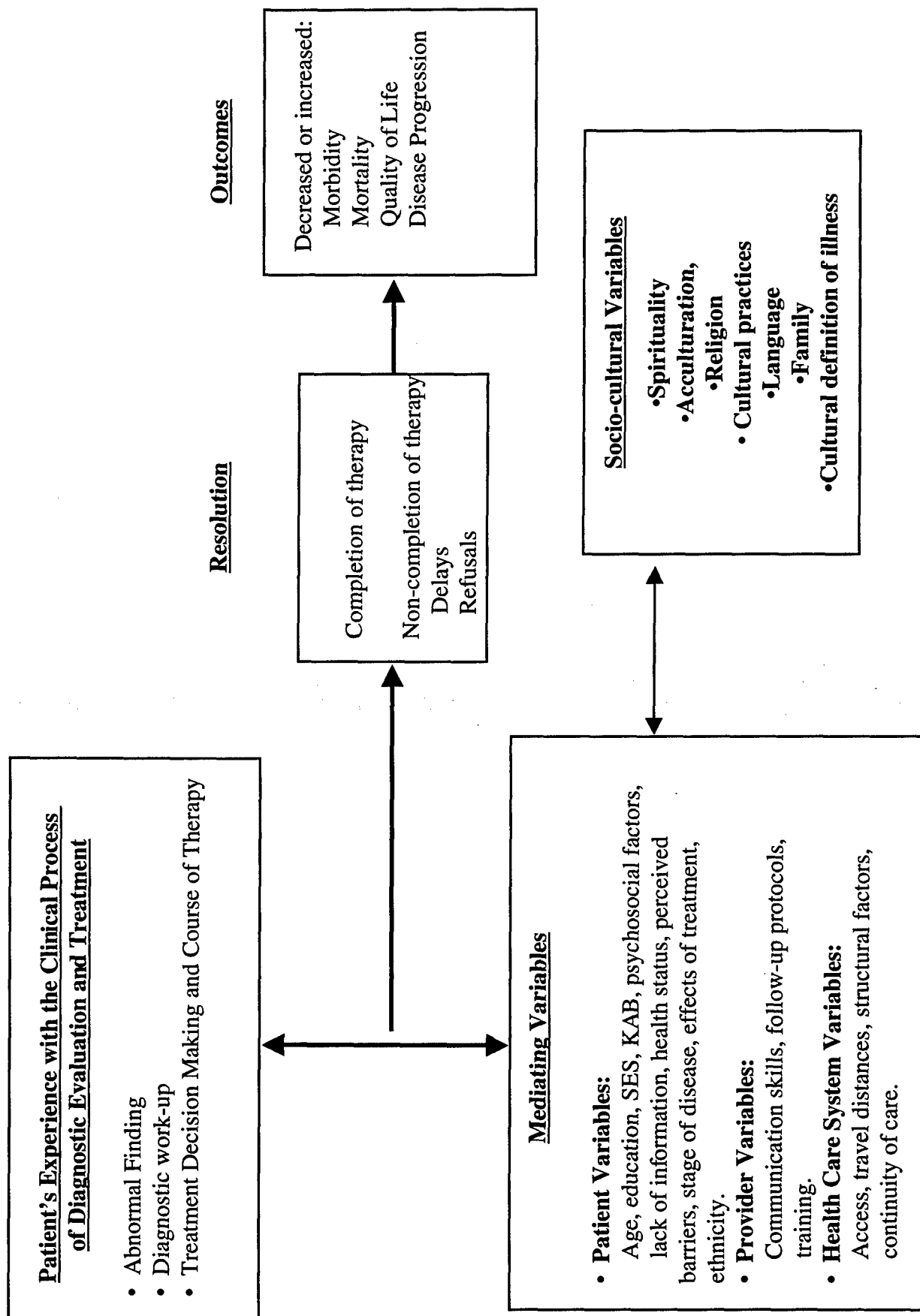
The investigator experienced personal health crises in the last year, which had some impact on the project timeline. These are discussed in the timeline of the Statement of Work (SOW) (Appendix J).

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APPENDIX A.

Conceptual Framework of Delays in Breast Cancer Care



APPENDIX B.

Interview Guide -Domains

- 1. General Health Practices**
- 2. Health Prior To BC Diagnosis**
- 3. Experiences Prior To Diagnosis**

**Provider/Clinic/Hospital
Family Involvement/Support
Friend Involvement/Support
Spiritual Support
Need for Information**

- 4. Experiences with Diagnosis**

**Provider Clinic/Hospital
Attitudes and Beliefs
Family Involvement/Support
Friend Involvement/Support
Spiritual Support
Need For Information**

- 5. Experiences with Planned Treatment**

**Provider/Clinic/Hospital
Patient Reaction to Treatment Plan
Family Involvement/Support
Friend Involvement/Support
Spiritual Support
Need For Information**

6. Treatment Completion and Non Completion -Barriers

For Each Individual Treatment Modality (surgery, Chemotherapy, radiation hormonal and immunotherapy:)

- **Socio-cultural (traditional practices, culturally held beliefs)**
- **Financial**
- **Transportation**
- **Interaction with Physician/Hospital**
- **Family/Friend Support**

APPENDIX C.

Discussion Guide for In Depth Interviews

GRAND TOUR QUESTIONS	INFORMATION QUESTIONS
1. Who do you see when you are not feeling well? 2. What was your health like before you learned about your cancer?	☛ Where do you usually go for care when you are sick or need advice about your health? ☛ Do you go for regular check-ups even when you are not sick? ☛ When, if ever, do you seek help from traditional healers? ☛ Did you have other health problems? ☛ How long had it been since you had seen a doctor? ☛ Did you visit someone else for advice on your health? (IF YES, WHO? (family, friend, traditional healer, spiritual leader)
3. How did you first notice that something had changed with your breasts? IF NO SYMPTOMS ASK: ↓ 4. How did you learn your breasts had changed ASK TO BOTH ↓ 5. What were you told to do about your exam or test after they said it was abnormal.	☛ Can you tell me if you noticed or felt any changes in your breast or symptoms before you were diagnosed? (IF YES, CONTINUE TO PROBE WITH:) ☛ How did you feel when you noticed _____ (USE SYMPTOM MENTIONED BY PARTICIPANT)? ☛ When did you visit someone to talk to about your symptoms for your breast problems? Where did you go? ☛ Did you feel you waited too long to see someone? ☛ Did you find out because of a scheduled breast exam and/or a mammogram done at the clinic/hospital? Where did you go? ☛ What were you told about your mammogram or breast exam? ☛ Can you tell me how you learned that you needed further tests? ☛ Who explained this to you? Was it in your language? ☛ Did you understand what was told to you? How did you feel? ☛ Was anyone with you while they explained the need for more tests?

6. What was your experience like at the clinic where you had your tests?	☛ How long was it before you went back for more tests? ☛ What type of tests were you told you needed? (Biopsy, etc.) ☛ Where else did you go for your tests? ☛ Who told you about the results of these tests? ☛ Who made the appointments for your test ☛ Do you think a lot of time went by before your next appointment? IF YES, ASK : ☛ What do you think were the reasons for this? ☛ Were you able to get a second opinion? ☛ Did you request more diagnostic test? ☛ How were these added test or second opinion paid for?
7. How did you feel about telling your family that more tests were needed?	☛ How did your family learn that you needed more tests? ☛ Did you talk to anyone about the need for more tests? Who? ☛ How important was it to have someone in your family to talk to you? Or to your provider? ☛ How did your _____ (FAMILY MEMBER) feel when you first told them you needed more tests to find out if you had breast cancer? ☛ Did you need help so that you could get to your appointments? ☛ Did you get help from someone? ☛ What kind of help did you get?
8. How did you feel about telling your friend(s) that more tests were needed?	☛ Did you talk to a friend about the problem with your breasts? IF NO, ASK: Why not? ☛ How important was it to have someone to talk to? ☛ What did your friend tell you when you told her/him that you needed more tests to find out if you had breast cancer? ☛ Did you need help so that you could get to your appointments? ☛ Did you get help from someone? ☛ What kind of help did you get? ☛ What kind of help did you need to pay for diagnostic services? ☛ Did you need someone take care of your children/grandchildren?
9. Were you given or told of any information explaining the tests you were going to have?	☛ Did someone talk to you about your problem or the tests you were going to have? ☛ Did you read something on your problem or the tests you were going to have? ☛ Did you talk to someone who knows about cancer? Who? ☛ Did you talk to someone in your community? Who?

10. How did the staff at the clinic/hospital tell you about your breast cancer diagnosis?	☛ After the tests, how did you learn about the diagnosis? ☛ How long after you your tests were you told of your diagnosis? ☛ Was it explained in your language? ☛ Who explained it to you? ☛ Was anyone with you when you were told of your diagnosis? ☛ What were you told would happen next? Did you feel you understood what was told to you by the doctor? ☛ Were you alone? Who else went with you? ☛ What could the physician or clinic staff have done differently to make the experience better? ☛ After learning of your diagnosis, how were you able to explain to your family what had been told to you earlier by the physician?
11. What was your reaction when you first heard of your breast cancer diagnosis?	☛ How did you feel? ☛ What kinds of thoughts came to you? ☛ Why did you feel that cancer happened to you? ☛ How did being told you had cancer make you feel ? ☛ Did you feel you had done something wrong and that is why you got the cancer? ☛ Did you feel that someone had wished bad things on you and that is why got the cancer?
12. What was your family's reaction to your diagnosis?	☛ Did you talk to anyone in your family about the diagnosis? ☛ Was it important to have someone to talk to? Who? ☛ How did _____ feel when you first told them you were diagnosed with breast cancer? ☛ What kinds of things did your family tell you when learning about diagnosis? ☛ What kind of support or help from family was most important to you during this time? (shopping/baby-sitting/preparing food) ☛ If you could, list three types of support or help you received? ☛ Who in the family was most helpful to you during this time? ☛ What did they do that made them of more help to you?
13. What kind of spiritual guidance was important at this time?	☛ Did you participate in healing/cleansing ceremonies and/or prayer /attending church service/ lighting candles/making a "promesa" at this time? ☛ Did you get something made or buy something for you, for spiritual protection to help you through this time? ☛ Can you tell me what those were? ☛ Were you allowed to keep these items with you while undergoing more tests?

14. How did you feel about telling your friend(s) about your diagnosis?	☛ Did you talk to a friend about the your diagnosis? ☛ Was it important for you to have a friend to talk to during this time? ☛ How did your friend feel when you first told them you had breast cancer?
15. Were you given information that had to do with your diagnosis of breast cancer	☛ Did someone talk to you about your diagnosis? ☛ Did you read something on your diagnosis? ☛ Did you talk to anyone who knows about cancer? ☛ Did you talk to anyone in your community that you trust about your diagnosis? ☛ Did you get information on breast cancer from community organizations? ☛ Did you talk to someone else who had breast cancer? ☛ Please tell me how this helped you? ☛ Were you told about cancer support groups? ☛ Did you feel a need to join a support group? ☛ What was most helpful to you? ☛ Did you get information in your own language? ☛ Did you write (in a journal or a diary) about your experiences during this time? ☛ During this time of your diagnosis did your music or art/craft reflect your experiences of being diagnosed with cancer?
16. What were you told about your treatment?	☛ What were you told about the recommended treatment plan? ☛ Were you given one treatment plan or were you informed about others? ☛ Who explained it? ☛ Did a family or friend go with you at this time? ☛ Did you go to another doctor or someone else you trusted for another opinion? ☛ Did you see someone else, other than a physician? ☛ Were there treatment options that were unavailable to you?
17. What was it like when you visited the hospital for your treatment?	☛ How hard was it for you and your family to travel to the hospital for your treatment? ☛ How far did you have to travel for treatment? Was your travel paid for? Or your family's? ☛ What was it like for you to be hospitalized? ☛ Were there times you found it hard to return to the hospital for your treatment? ☛ Were you asked how you would pay for your treatments? Did your health plan pay? ☛ Who decided what type of treatment would be paid? ☛ Did this affect the type of treatment you received? ☛ Were family members allowed to go in with you for your treatment?

18. What was your reaction towards your treatment?	☛ How did you feel about what you were told? ☛ Did you think that the treatment would remove the cancer? ☛ What did you think would happen once you started treatment? ☛ What were other things you thought about? ☛ Were you worried about how you would pay for your treatment? ☛ Were you worried about whether your body was strong enough to handle the treatment? ☛ When did you decide to go in for your first treatment? ☛ Was it longer than you wanted to wait? Why was this? (PROBE: PHYSICIAN DID NOT REFER, IF IHS WOULD PAY, MEDICARE ELIGIBILITY PROCESS, PARTICIPATED IN A HEALING CEREMONY,)
19. What was your family's reaction to the planned treatment?	☛ Did you talk to anyone about the planned treatment? ☛ What did your family think of the treatment plan? ☛ Did they think you should get a second opinion? ☛ Was your family worried about how you would pay for your treatment? ☛ What kind of support or help from family was most important to you? (shopping/baby-sitting/preparing food) ☛ Did you talk to someone in your family who had received treatment for cancer? Who was this? ☛ Who of your family was especially helpful to you? ☛ What did they do that was so helpful?
20. What kind of spiritual guidance was important at this time?	☛ Did you participate in healing/cleansing ceremonies and/or prayer /attending church service/ lighting candles/making a "promesa" at this time? ☛ Did you get something made or bought something for spiritual protection to help you through this time? ☛ Can you tell me what those were?
22. What was it like for your friends during this time?	☛ Did you talk to a friend(s) about the your treatment? ☛ How important was it to have someone to talk to? ☛ How did your friend(s) feel towards you ☛ Did you receive help from your friends at this time? What kind of help?

23. Were you told or given information about your treatment plan for breast cancer?	☛ Did someone give you information about cancer treatment? ☛ Did you read something on the type of treatments planned? ☛ Did you talk to anyone who knew about the treatment you would have? ☛ Did you talk to anyone in your community that you trust about the planned treatment? ☛ Did you get information on breast cancer from community organizations? ☛ Did you talk to someone else who had breast cancer? ☛ Did this help you? How? ☛ Were you told about cancer support groups? ☛ Did you feel a need to join a support group? ☛ What was most helpful to you? ☛ Did you get information in your own language?
24. What was your experience with your surgery?	IF PT. DID NOT HAVE THE SURGERY AS PLANNED, PROBE: ☛ What happened that you did not have the surgery as planned? ☛ Did you go back and have it? IF YES, PROBE: ☛ What made things different that you could have the surgery? ☛ Did you see someone else that helped you feel better about getting your surgery? Who? IF NO, PROBE: ☛ What happen that you did not have the surgery? ☛ Did your physician or anyone from the hospital contact you regarding your decision not to have surgery? ☛ Did you see someone else that tried to help you get your surgery? Who? ☛ Did you decide to have a cleansing or healing ceremony before deciding on surgery? ☛ Is there something about the surgery and what it does to you that made you decide not to have it? IF YES: SAY: Please explain ☛ Is there anything that would have helped you get your surgery for your breast cancer? ☛ Did you have a hard time with financial coverage for your surgery? IF YES, ASK, How was the surgery paid for? ☛ Where was your surgery scheduled? Was it far from your home? IF YES: ASK, How Far? ☛ Was it hard to get transportation to the hospital? IF YES, HOW MANY MILES IS IT FROM YOUR HOME? ☛ Was it hard to get someone to care for your loved ones?

Surgery Continued.	If PT. HAD THE SURGERY CONTINUE PROBE: ☛ What type of surgery was recommended? ☛ How long was it before you had the surgery? ☛ Did you have a cleansing or healing ceremony to help prepare you for your surgery? ☛ How did the medical staff accept this preparation? ☛ Where did your surgery take place? ☛ What was the experience with surgery like? ☛ Were you scheduled for surgery soon? ☛ Did you experience difficulties (transportation, second thoughts about the procedure, insurance) in getting the surgery done? ☛ Did you have a hard time getting your treatment paid for? ☛ Did they speak with you about breast reconstruction?
25. What was your experience like while you were in the hospital?	☛ Did you have clinic staff or anyone else explain how you would feel after the surgery? ☛ Did anyone explain how you would feel once the lymph nodes are removed? Was it explained in your language? ☛ Did anyone explain the care you would need after you were discharged for your surgery? Was it explained in your language? ☛ Did you have prescribed medications, such as pain medicine, when you were discharged from the hospital? ☛ Did you understand which medicine was for your treatment and which was for pain? ☛ Did you receive instructions for the medicine in way that you understood about its side effects?
26. What was it like for your family during the time of your surgery?	☛ How did they feel after your surgery? ☛ How did your family help while you were in the hospital? ☛ Was someone with you while you stayed in the hospital? ☛ Did your family get to visit you while you were in the hospital? ☛ How did you feel towards your family after your surgery?
27. What was it like for your friends during the time of your surgery?	☛ Did your friends come to visit you while you were in the hospital? ☛ How did you feel towards your friends after your surgery? ☛ Did your friends help you or your family while you was in the hospital? How?

28. What other treatments were planned for your breast cancer.
(chemotherapy)

☛ Was chemotherapy planned as part of your treatment?
IF PATIENT SAYS NO THE CHEMOTHERAPY WAS NOT PLANNED CONTINUE TO RADIATION:

IF PATIENT SAYS IT WAS PLANNED BUT DID NOT GET IT DONE, PROBE:

- ☛ What happened that you did not have the chemotherapy?
- ☛ What hospital was your chemotherapy scheduled at? Is this far from your home? **IF YES: HOW MANY MILES?**
- ☛ Did your physician or anyone from the hospital contact you regarding your decision not to have your chemotherapy?
- ☛ Did you see someone else for your treatment?
- ☛ Is there anything that would have helped you get your chemotherapy for your breast cancer?
- ☛ Was it difficult to get health coverage for this treatment?
- ☛ Were you scared of how the treatment would affect you?
- ☛ Did you need to care for loved ones?

IF PATIENT SAYS YES PLANNED AND DID GET IT, THEN PROBE:

- ☛ How long were you going for chemotherapy treatment?
- ☛ Were there times when it was difficult for you to keep your appointments? Why?
- ☛ Was it difficult getting your treatment covered under your insurance or any other type of payment plan?
- ☛ What hospital was your chemotherapy scheduled at? is this far from your home?
- ☛ Did you see someone else that helped you with the side effects of your chemotherapy?

29. What other treatments were planned for your breast cancer.
(radiation)

☛ Was radiation planned as part of your treatment?
IF PATIENT SAYS NO RADIATION WAS NOT PLANNED CONTINUE TO HORMONAL:

IF PATIENT SAYS IT WAS PLANNED BUT DID NOT GET IT DONE, PROBE:

- ☛ What happened that you did not have the radiation?
- ☛ What hospital was your radiation scheduled at? Is this far from your home? **IF YES, ASK: HOW MANY MILES?**
- ☛ Did your physician or anyone from the hospital contact you regarding your decision not to have your radiation?
- ☛ Did you see someone else for your treatment?
- ☛ Is there anything that would have helped you get your radiation for your breast cancer?
- ☛ Was it difficult to get health coverage for this treatment?
- ☛ Were you afraid of how the radiation would affect your body?
- ☛ Did you need to care for your loved ones?

Radiation Continued 30. What other treatments were planned for your breast cancer (hormonal)	IF PATIENT SAYS YES PLANNED AND DID GET IT, THEN PROBE: ☛ How long were you going for radiation treatment? ☛ Were there times when it was difficult for you to keep your appointments? Why? ☛ Was it difficult getting your treatment covered under your insurance or any other type of payment plan? ☛ What hospital was your radiation scheduled at? Is this far from your home? ☛ Did you also see someone else that helped you with the side effects of the radiation? How did they help? ☛ Was hormonal therapy planned as part of your treatment? IF PATIENT SAYS NO THE HORMONAL WAS NOT PLANNED CONTINUE TO IMMUNOTHERAPY: IF PATIENT SAYS IT WAS PLANNED BUT DID NOT GET IT DONE, PROBE: ☛ What happened that you did not have hormonal therapy? ☛ Did your physician or anyone from the hospital contact you regarding your decision not to have your hormonal therapy? ☛ Did you see someone else for your treatment? ☛ Is there anything that would have helped you get your hormonal therapy for your breast cancer? ☛ Was it difficult to get health coverage for this treatment? ☛ Were you afraid of how the hormonal therapy would affect your body? ☛ Did you need to care for your loved ones? IF PATIENT SAYS YES IT WAS PLANNED AND DID GET IT DONE , THEN PROBE: ☛ How long were/are you going for hormonal therapy? ☛ Did you have a hard time getting your treatment covered under your insurance or any other type of payment plan? ☛ Did you also see someone else that helped you with the side effects of hormonal therapy? IF YES: Who? ☛ Did you take herbs or other things to help you with the side effects of the treatment? IF YES: What? ☛ Did they test you to see if you were receptor positive? ☛ Did they explain the advantages and disadvantages of hormonal therapy?
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31. What other treatments were planned for your breast cancer. (Immunotherapy)	☛ Was Immunotherapy planned as part of your treatment? IF PATIENT SAYS NO THE IMMUNOTHERAPY WAS NOT PLANNED CONTINUE TO DEMOGRAPHIC SECTION: IF PATIENT SAYS IT WAS PLANNED BUT DID NOT GET IT DONE, PROBE: ☛ What happened that you did not have the immunotherapy? ☛ What hospital was your immunotherapy scheduled at? Is this far from your home? ☛ Did your physician or anyone from the hospital contact you regarding your decision not to have your immunotherapy? ☛ Did you see someone else for your treatment? ☛ Is there anything that would have helped you get your immunotherapy for your breast cancer? ☛ Was it difficult getting health insurance coverage for this treatment? ☛ Were you afraid of how the immunotherapy would affect your body? ☛ Did you need to care for your loved ones? IF PATIENT SAYS YES PLANNED AND DID GET IT DONE , THEN PROBE: ☛ How long were you going for immunotherapy? ☛ Were there times when it was difficult for you to keep your appointments? Why? ☛ Was it difficult getting your treatment covered under your insurance or any other type of payment plan? ☛ What hospital was your immunotherapy scheduled? Is this far from your home? ☛ Did you also see someone else that helped with the side effects of your immunotherapy?
32. Did anyone speak with you about taking part in a clinical trial?	☛ Did anyone ask you to participate in a clinical trial? ☛ Did anyone explain the advantages and disadvantages of participating in one?
33. What is your outlook on life since your diagnosis of cancer?	☛ How have you felt since your diagnosis of cancer? ☛ Looking back, is there something you would do different now? ☛ How has your diagnosis of cancer changed you? How has it changed your family?

DEMOGRAPHICS

Now, I would like to ask a few questions to help me understand more about you and the answers you gave us.

AGE

Interviewer: Please ask the following questions. Circle all responses.

1. How old were you on your last birthday?

(YEARS).

88 DK
99 refused

BIRTH PLACE

2. Where were you born? Please tell me the state and country.

<u>STATE</u>	<u>COUNTRY</u>
ALABAMA	UNITED STATES OF AMERICA
ALASKA	UNITED STATES OF AMERICA
ARIZONA	UNITED STATES OF AMERICA
ARKANSAS	UNITED STATES OF AMERICA
CALIFORNIA	UNITED STATES OF AMERICA
COLORADO	UNITED STATES OF AMERICA
CONNECTICUT	UNITED STATES OF AMERICA
DELAWARE	UNITED STATES OF AMERICA
DISTRICT OF COLUMBIA	UNITED STATES OF AMERICA
FLORIDA	UNITED STATES OF AMERICA
GEOORGIA	UNITED STATES OF AMERICA
HAWAII	UNITED STATES OF AMERICA
IDAHOW	UNITED STATES OF AMERICA
ILLINOIS	UNITED STATES OF AMERICA
INDIANA	UNITED STATES OF AMERICA
IOWA	UNITED STATES OF AMERICA
KANSAS	UNITED STATES OF AMERICA
KENTUCKY	UNITED STATES OF AMERICA
Louisiana	UNITED STATES OF AMERICA
MAINE	UNITED STATES OF AMERICA
MARYLAND	UNITED STATES OF AMERICA
MASSACHUSETTS	UNITED STATES OF AMERICA
MICHIGAN	UNITED STATES OF AMERICA
MINNESOTA	UNITED STATES OF AMERICA
MISSISSIPPI	UNITED STATES OF AMERICA
MISSOURI	UNITED STATES OF AMERICA
MONTANA	UNITED STATES OF AMERICA
NEBRASKA	UNITED STATES OF AMERICA
NEVADA	UNITED STATES OF AMERICA
NEW HAMPSHIRE	UNITED STATES OF AMERICA
NEW JERSEY	UNITED STATES OF AMERICA
NEW MEXICO	UNITED STATES OF AMERICA
NEW YORK	UNITED STATES OF AMERICA
NORTH CAROLINA	UNITED STATES OF AMERICA
NORTH DAKOTA	UNITED STATES OF AMERICA
OHIO	UNITED STATES OF AMERICA
OKLAHOMA	UNITED STATES OF AMERICA
OREGON	UNITED STATES OF AMERICA
PENNSYLVANIA	UNITED STATES OF AMERICA
RHODE ISLAND	UNITED STATES OF AMERICA
SOUTH CAROLINA	UNITED STATES OF AMERICA
SOUTH DAKOTA	UNITED STATES OF AMERICA
TENNESSEE	UNITED STATES OF AMERICA
TEXAS	UNITED STATES OF AMERICA
UTAH	UNITED STATES OF AMERICA
VIRGINIA	UNITED STATES OF AMERICA
WASHINGTON	UNITED STATES OF AMERICA
WEST VIRGINIA	UNITED STATES OF AMERICA
WISCONSIN	UNITED STATES OF AMERICA
WYOMING	UNITED STATES OF AMERICA
AFRICA	AFRICA
AMERICA	AMERICA
ASIA	ASIA
AUSTRALIA	AUSTRALIA
BELGIUM	BELGIUM
BRAZIL	BRAZIL
CANADA	CANADA
CHINA	CHINA
FRANCE	FRANCE
GERMANY	GERMANY
ITALY	ITALY
JAPAN	JAPAN
MEXICO	MEXICO
NETHERLANDS	NETHERLANDS
RUSSIA	RUSSIA
SPAIN	SPAIN
SWITZERLAND	SWITZERLAND
UNITED KINGDOM	UNITED KINGDOM
USSR	USSR
ZIMBABWE	ZIMBABWE

88 DK
99 refused

EDUCATION

2. What is the highest level of education you have completed?

_____ years if less than 12

- 01 High School, GED
02 Some college, technical or vocational school
03 Bachelor's degree
04 Some graduate/professional course work
05 Advanced degree (Masters, Ph.D. M.D. etc.)
88 DK
99 refused

DEMOGRAPHICS CONTINUED.

ETHNIC/RACIAL IDENTIFICATION

3. How would you describe your ethnic/racial origin?

- 06 White
07 Black or African American
08 Navajo
09 American Indian (other than Navajo)
10 Hispanic_____ IF YES:ASK Which Hispanic Group?
11 Asian or Pacific Islander
12 Other Native American (Hawaiian, Alaskan Native)
13 Other: Please specify_____
88 DK
99 refused

MARITAL STATUS

4. Which of the following best describes your current situation:

- 14 Married
15 Widowed
16 Divorced
17 Separated
18 Never been married
19 Member of unmarried couple
88 DK
99 Refused

INCOME

5. I will now read to you different household incomes. Please tell me when I get close to the amount closest to yours.

- 20 Less than \$5000
21 Less than \$10,000
22 Less than \$20,000
23 Less than \$30,000
24 Less than \$40,000
25 Less than \$50,000
26 \$50,000 or more
88 DK
99 refused

OCCUPATION

6. How many people are supported on this income?
— — #Of people.

88 DK
99 refused

7. What has been your usual job or occupation?

Discussion Guide for In Depth Interviews

GRAND TOUR QUESTIONS	INFORMATION QUESTIONS
1. Who do you go to see when you are not feeling well? 2. How is your present health?	☛ Where do you usually go for care when you are sick or need advice about your health? ☛ Do you go for regular check-ups even when you are not sick? ☛ When, if ever, do you seek help from traditional healers? ☛ Do you have health problems? ☛ How long has it been since you have seen a doctor? ☛ Do you visit someone else for advice on your health? (IF YES, WHO? family, friend, traditional healer, spiritual leader)
3. Can you tell me how you first learned about _____ (participant's) breast cancer diagnosis 4. Can you tell me what you felt when you first heard she had "cancer"	☛ Who told you about the diagnosis? ☛ When did you first learn about the diagnosis? ☛ Were you told before or after treatment began? ☛ How did you feel learning of the diagnosis when you did? ☛ How did you feel when you first heard that she was diagnosed with breast cancer? ☛ Why did you think she was diagnosed with the cancer? ☛ Did you feel she did something to bring on her cancer ? ☛ Did you think that you could also get her cancer? ☛ Did other family members also feel this way? ☛ Do you think that she will get well ? ☛ Do you think there are things we can do so that we don't get cancer?

5. Can you tell me what types of things helped you deal with her diagnosis?	☛ Did you talk about the diagnosis with _____ (participant) ☛ Did you participate in healing/cleansing ceremonies and/or prayer attending church service/ lighting candles/making a "promesa" with her or alone at this time? ☛ Did you talk to other relatives? Who ? ☛ Did you talk to friends? ☛ Did you talk to someone for spiritual guidance? ☛ Did you get information on breast cancer? ☛ Did you talk to someone who knows about cancer? who? ☛ Did you talk to someone in your community that you trust? who?
6. Can you tell me what types of things helped _____ (participant) deal with her diagnoses?	☛ Did you go with her to the appointments? ☛ Did you offer help with transportation or money to get her to the appointments? ☛ What other things helped her during this time? (making meals, taking care of children/grandchildren, sitting with her at the doctor's office, talking to her doctors) ☛ Who else in the family helped with these things? ☛ Do you think that you were able to help her enough? ☛ Did you feel she needed more help than what you had to offer? Like what?
7. Can you tell me how you felt about the help you gave her during this time?	☛ Did you feel it was important for you to help her? Why? ☛ Did you feel burden because there was not enough time or money to help her? ☛ Did you feel you needed to be strong for her or the rest of the family? ☛ Did you feel your help was needed? ☛ Did you feel frustrated because it was hard for her talk to you? ☛ Did you feel that she would talk to you when she was ready?
8. How did you feel when you visited the hospital/ physician with _____ (participant)'s for her treatments.	☛ Did you go with _____ for her treatments? ☛ What was it like for you and other family members after she her treatments? ☛ Were there times when you found it hard to take _____ to the doctor/hospital for her treatments?

9. How did you feel about the treatment planned for _____? (participant's)	☛ Did _____ talk to you or other family members about the planned treatment? ☛ What did your family think of the treatment? ☛ Did you or other family members think _____ should get a second opinion? ☛ Were you worried about how _____ would pay for her treatment? ☛ Were you worried about how _____ would get to her treatments?
10. What kind of spiritual guidance was important to you at this time?	☛ Did you or other family members participate in healing/cleansing ceremonies and/or prayer /attending church service/ lighting candles/making a "promesa" at this time? ☛ Did you or other family members get something made or bought something for spiritual protection to help you through this time? Can you tell me what those were?
11. Were you given any information about breast cancer treatment during this time?	☛ Did someone give you information about the treatment plan? ☛ Did you get information in your own language? ☛ Did you read something on the type of treatments planned? ☛ Did you talk to _____ about her treatment? ☛ Did you talk to anyone in your community that you trust about the treatment planned for _____ (participant)? ☛ Were you told about cancer support groups? ☛ Did you feel a need to join a support group?
12. What was it like for you during the time of her surgery?	☛ Did _____ have surgery for breast cancer? IF FAMILY MEMBER MENTIONS THAT PT. DID NOT HAVE THE SURGERY AS PLANNED PROBE: ☛ What happened that she did not have the surgery as planned? ☛ Did she decide to go back and have it? ☛ How did you feel about her not having the surgery? ☛ Did you try to talk her into having her surgery? ☛ Did you try to get her to talk to someone else about her surgery? Who? ☛ Did you feel she should see someone else for her surgery? Who? ☛ Do you think there was something that could have helped her get her surgery for her breast cancer? What?

Surgery Continued.	IF FAMILY MEMBER HAS NO FURTHER KNOWLEDGE OF SURGERY GO ON TO CHEMOTHERAPY. IF FAMILY MEMBER SAYS YES, PT HAD SURGERY PROBE: ☛ How did you feel after her surgery? ☛ Did she need help with (errands, children etc.) while she was in the hospital? Did she get help? ☛ Were you able or allowed to stay in the hospital with her ? ☛ Did you visit her while she was in the hospital? ☛ Was chemotherapy planned as part of her treatment? IF NO THE CHEMOTHERAPY WAS NOT PLANNED OR NO KNOWLEDGE OF IT CONTINUE TO RADIATION: IF FAMILY MEMBER HAS SAYS IT WAS PLANNED BUT DID NOT GET IT DONE, PROBE: ☛ What happened that she did not have the chemotherapy? ☛ Did she see someone else for her treatment? IF YES: WHO? ☛ Is there anything that would have helped her get her chemotherapy for her breast cancer? ☛ Were you worried of how the treatment would affect her ? IF FAMILY MEMBER SAYS YES PLANNED AND DID GET IT, THEN PROBE: ☛How did you feel about her chemotherapy treatments?
13. What other treatments did _____ (participant) have?	

14. What other treatments did _____ (participant) have?	☛ Was radiation planned as part of her treatment? IF FAMILY MEMBER SAYS RADIATION NOT PLANNED OR NO KNOWLEDGE OF IT CONTINUE TO HORMONAL: IF FAMILY MEMBER SAYS IT WAS PLANNED BUT DID NOT GET IT DONE, PROBE: ☛ What happened that she did not have the radiation? ☛ Did she see someone else for her treatment? IF YES: WHO? ☛ Is there anything that would have helped her get her radiation for her breast cancer? ☛ Were you worried about how the radiation would affect her body? IF FAMILY SAYS YES PLANNED AND DID GET IT, THEN PROBE: How did you feel about her radiation treatments?
15. What other treatments did _____ (participant) have?	☛ Was hormonal therapy planned as part of the treatment? IF FAMILY MEMBER SAYS HORMONAL THERAPY NOT PLANNED OR NO KNOWLEDGE OF IT CONTINUE TO IMMUNOTHERAPY: IF FAMILY MEMBER SAYS IT WAS PLANNED BUT DID NOT GET IT DONE, PROBE: ☛ What happened that she did not have hormonal therapy? ☛ Did she see someone else for her treatment? IF YES: WHO? ☛ Is there anything that would have helped her get her treatment? ☛ Were you worried about how the hormonal therapy would affect her body? IF FAMILY SAYS YES IT WAS PLANNED AND DID GET IT DONE , THEN PROBE: How did you feel about her hormonal treatment?

15. What other treatments did _____ (participant) have?	☛ Was immunotherapy planned as part of your treatment? IF FAMILY MEMBER SAYS IMMUNOTHERAPY NOT PLANNED OR NO KNOWLEDGE OF IT CONTINUE TO DEMOGRAPHIC SECTION. IF FAMILY MEMBER SAYS IT WAS PLANNED BUT DID NOT GET IT DONE, PROBE: ☛ What happened that she did not have immunotherapy? ☛ Did she see someone else for her treatment? IF YES: WHO? ☛ Is there anything that would have helped her get her treatment? ☛ Were you worried about how the treatment would affect her body? IF FAMILY SAYS YES IT WAS PLANNED AND DID GET IT DONE , THEN PROBE: How did you feel about her immunotherapy treatment?
16. How have you been since your _____ was diagnosed with breast cancer?	☛ How has _____ cancer changed your life? How? ☛ Thinking about that time, is there something you think could have been different? What? ☛ Do you think that the cancer diagnosis has changed _____ life/ How?

DEMOGRAPHICS

Now, I would like to ask a few questions to help me understand more about you and the answers

AGE

Interviewer: Please ask the following questions. Circle all responses.

1. How old were you on your last birthday?

_____ (YEARS).

88 DK
99 refused

BIRTH PLACE

2. Where were you born? Please tell me the state and country.

STATE	COUNTRY
Alabama	USA
Alaska	USA
Arizona	USA
Arkansas	USA
California	USA
Colorado	USA
Connecticut	USA
Delaware	USA
District of Columbia	USA
Florida	USA
Georgia	USA
Hawaii	USA
Idaho	USA
Illinois	USA
Indiana	USA
Iowa	USA
Kansas	USA
Kentucky	USA
Louisiana	USA
Maine	USA
Maryland	USA
Massachusetts	USA
Michigan	USA
Minnesota	USA
Mississippi	USA
Missouri	USA
Montana	USA
Nebraska	USA
Nevada	USA
New Hampshire	USA
New Jersey	USA
New Mexico	USA
New York	USA
North Carolina	USA
North Dakota	USA
Ohio	USA
Oklahoma	USA
Oregon	USA
Pennsylvania	USA
Rhode Island	USA
South Carolina	USA
South Dakota	USA
Tennessee	USA
Texas	USA
Utah	USA
Vermont	USA
Virginia	USA
Washington	USA
West Virginia	USA
Wisconsin	USA
Wyoming	USA

88 DK
99 refused

EDUCATION

2. What is the highest level of education you have completed?

____ years if less than 12

01 High School, GED
02 Some college, technical or vocational school
03 Bachelor's degree
04 Some graduate/professional course work
05 Advanced degree (Masters, Ph.D. M.D. etc.)
88 DK
99 refused

DEMOGRAPHICS CONTINUED. ETHNIC/RACIAL IDENTIFICATION	3. How would you describe your ethnic/racial origin? 06 White 07 Black or African American 08 Navajo 09 American Indian (other than Navajo) 10 Hispanic _____ IF YES:ASK Which Hispanic Group? 11 Asian or Pacific Islander 12 Other Native American (Hawaiian, Alaskan Native) 13 Other: Please specify _____ 88 DK 99 refused
MARITAL STATUS ➡	4. Which of the following best describes your current situation: 14 Married 15 Widowed 16 Divorced 17 Separated 18 Never been married 19 Member of unmarried couple 88 DK 99 Refused
INCOME ➡	5. I will now read to you different household incomes. Please tell me when I get close to the amount closest to yours. 20 Less than \$5000 21 Less than \$10,000 22 Less than \$20,000 23 Less than \$30,000 24 Less than \$40,000 25 Less than \$50,000 26 \$50,000 or more 88 DK 99 refused

OCCUPATION ➡	6. How many people are supported on this income? __ __ #Of people. 88 DK 99 refused 7. What has been your usual job or occupation? _____ _____
---------------------	---

APPENDIX D.

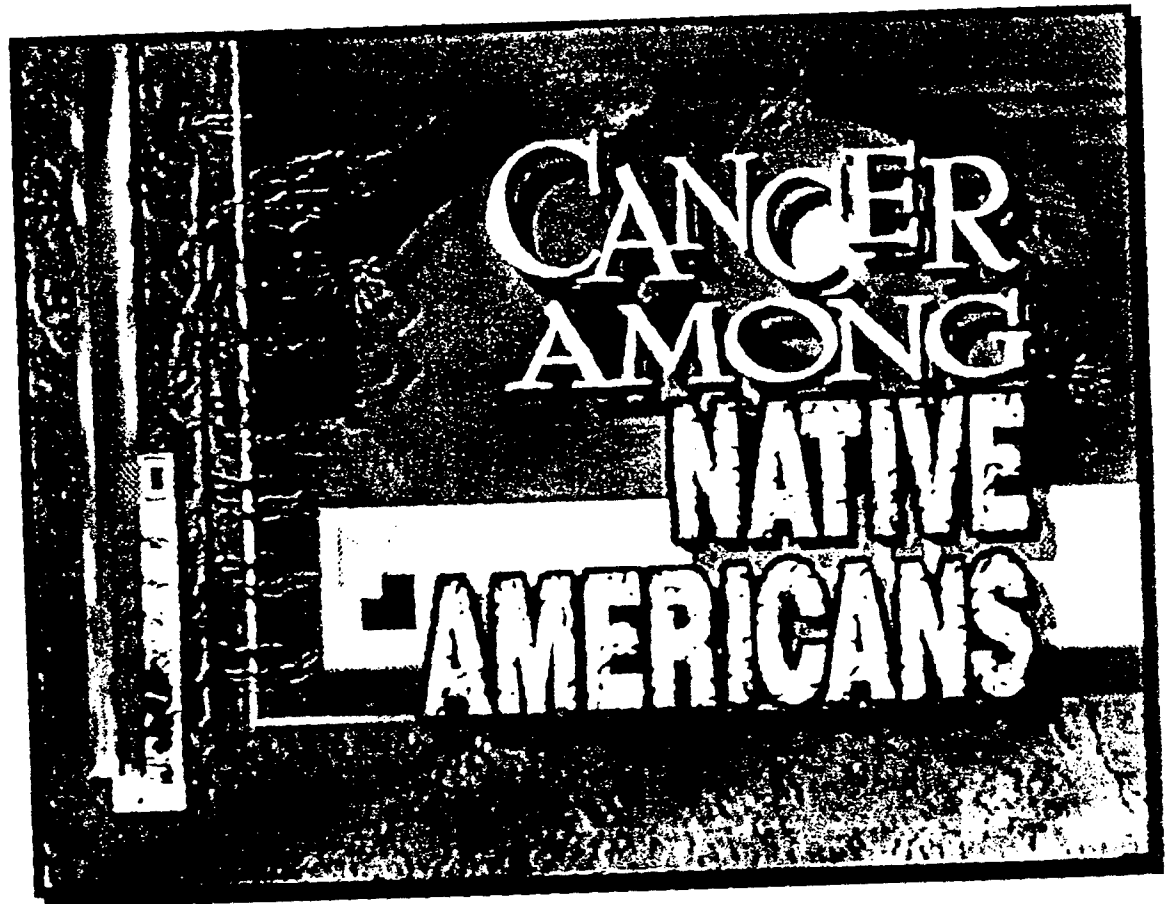
Native American Breast Cancer Survivors:

*Stories of Our Personal Reactions to
Our Breast Cancer Diagnosis*



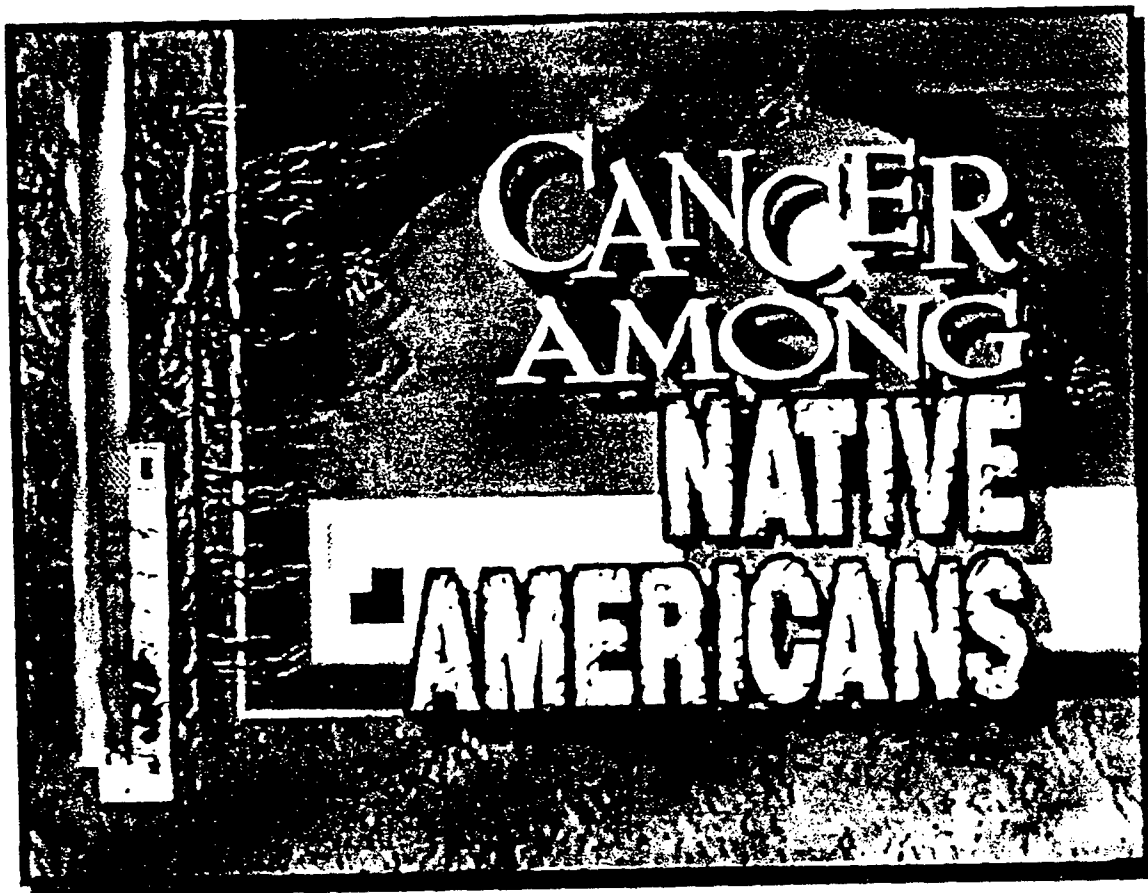
Native American Breast Cancer Survivors:

Family's Reaction to Diagnosis



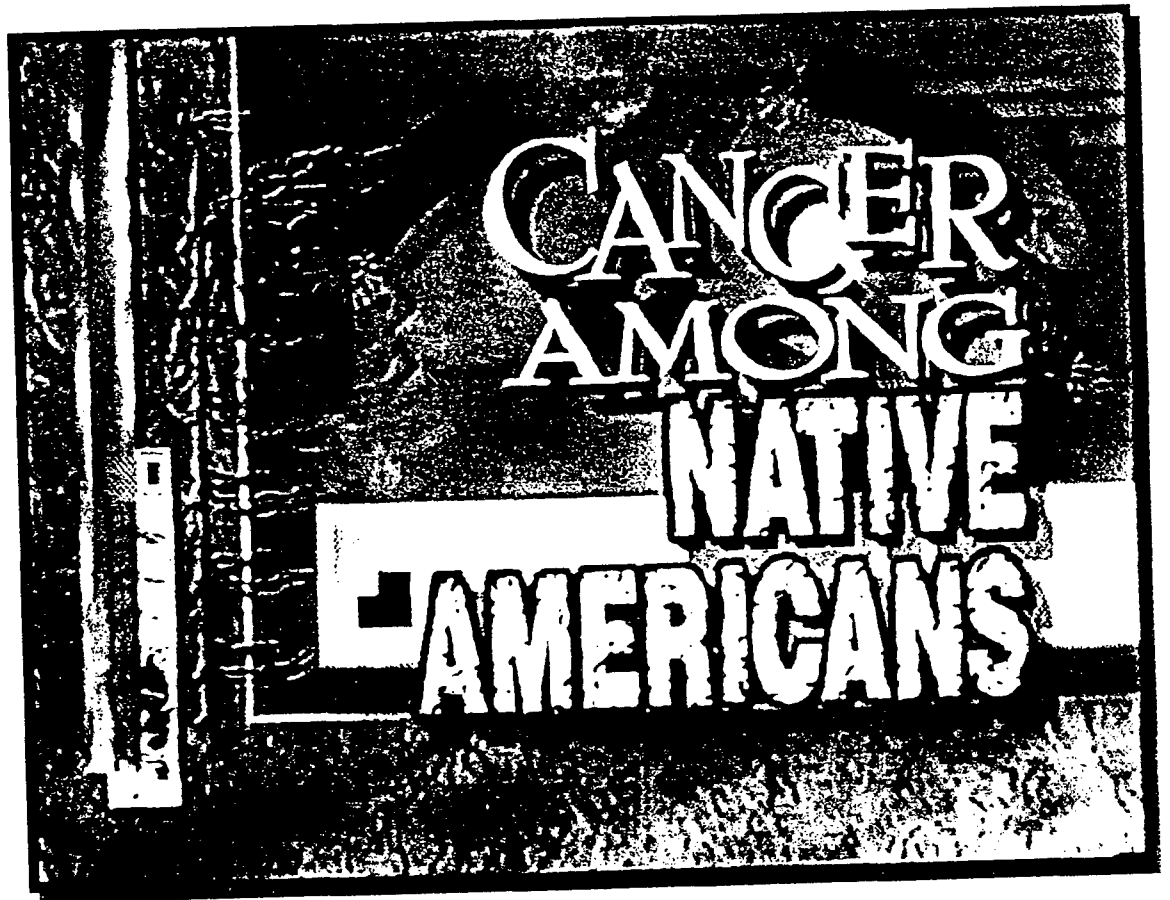
**Native American Breast Cancer
Survivors:**

***Stories of Our Breast Cancer
Treatments***



Native American Breast Cancer Survivors:

Outlook on Life



Project Supported By:



The Graham Foundation, Colorado Springs, CO
The Breast Cancer Fund, San Francisco, CA
The Kettering Family Foundation, Denver, CO
AVON Breast Health Leadership Award, NYC, NY
Native American Cancer Research, Pine, CO



For Further Information, Contact:

Native American Cancer Research
3022 South Nova Road
Pine, CO 80740-7830
(303) 838-9359 FAX (303) 838-7629
E-mail: natamcan@aol.com
WEB PAGE: <http://www.aclin.org/code/nac>

Layout, Graphics & Photo Enhancements by: Rick Clark
Morning Dew Computer Productions, Pine, CO
(E-Mail: dontdoam@aol.com)

Cover Graphic: Neil Thompson

Graphic Layout/Desktop Publishing: Linda Burhansstipanov

Transcriptions: Lisa Castro

Organization, Coordination, Refinement: Linda Burhansstipanov [Western Cherokee], Nina Capelouto [Apache], Della Bad Wound [Oglala Sioux]

In Honor & Memory of *Katherine Big Hail* [Crow]

APPENDIX E.

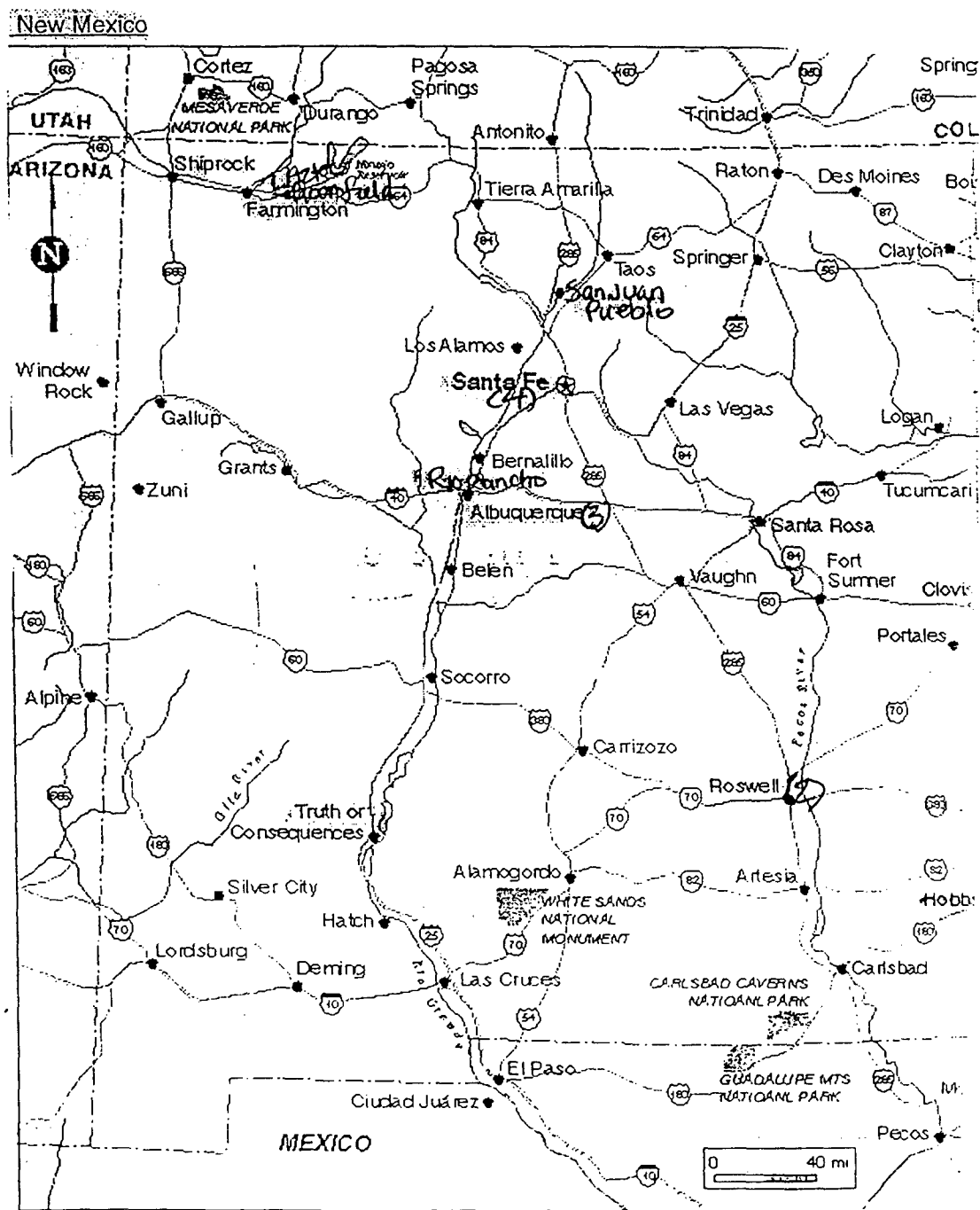
GEOGRAPHIC LOCATION OF PARTICIPANTS

7 00

(Non-Hispanic White)

Peralta
Shiprock

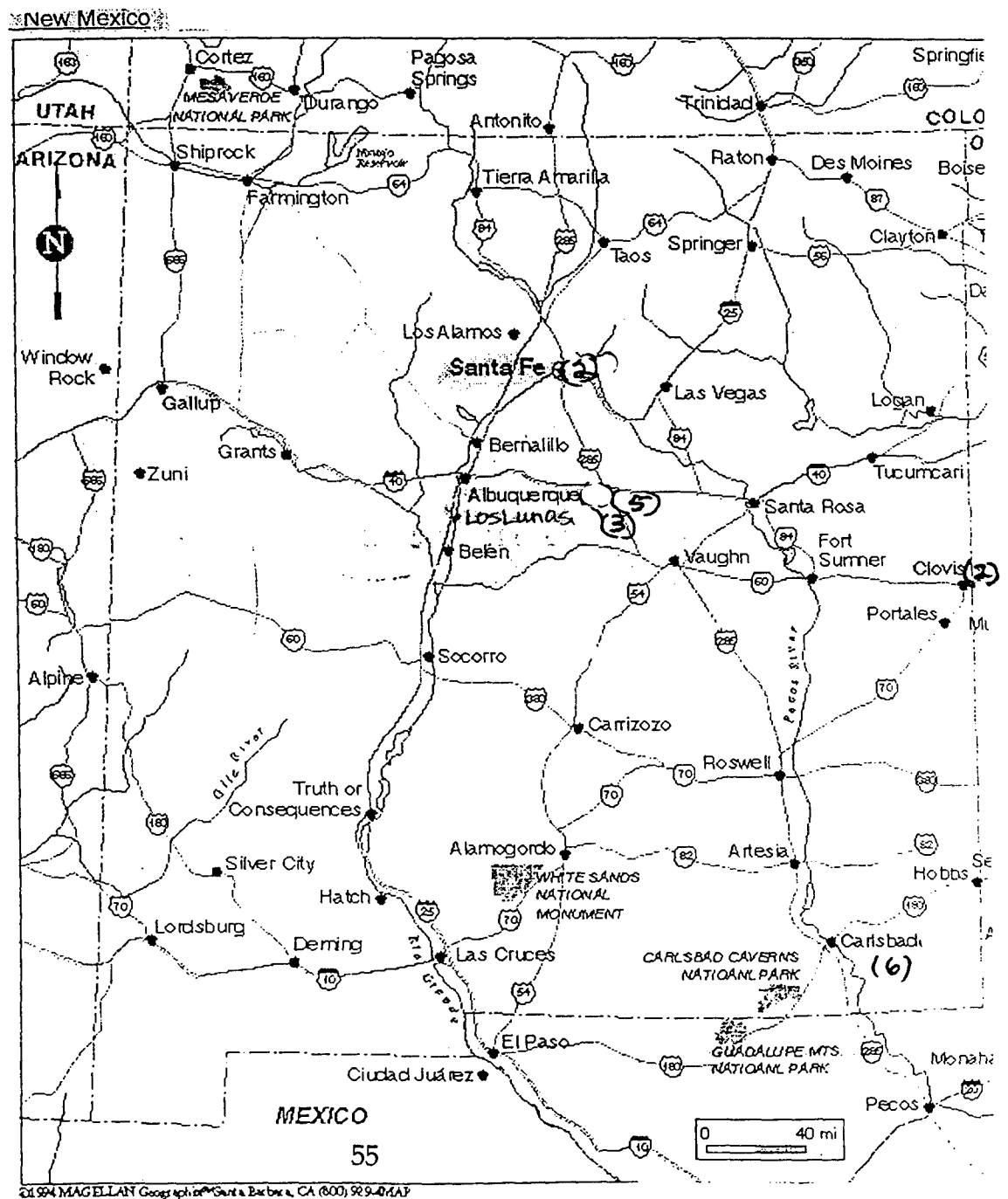
Clovis
San Juan Pueblo
Farmington
Embudo
Ruidoso



4 01
(Hispanic)

Albuquerque - 5
Los Lunas - 3

Embudo



Shiprock - 5
Gallup - 2
Teec - 2
Farmington
Albuquerque
Thoreau
Twin Lakes
Zuni
Jemez Pueblo
Magdalena
Bluewater Lake

Pueblo Pintado
Gamerco
San Fide
Coyote Canyon
Sanostee
San FLDNS Pueblo
Isleta
Many Farms
Collidge
Gerson

Jicarilla
Apache
Indian
Reservat

COLOFADO

UTAH

ARIZONA

Mescalero

Coolidge, AZ
P.R.
Dover

APPENDIX F.

PATIENT DIAGNOSTIC AND TREATMENT SUMMARY REPORT ABSTRACT FORM

PART I.

DEMOGRAPHICS

Study Id #: _____ Ethnicity Code: _____ (If Code 05, specify: _____)
Clinic #: _____ Residence at DX: _____ Zip Code: _____

PART II. BREAST AND CERVICAL CANCER PROGRAM DATA

A. SCREENING CYCLE (on data file).

B. DIAGNOSTIC INFORMATION

Diagnostic Procedures: _____ (multiple responses: 1-6,9)
Final Diagnosis: _____ (1-3) Stage at diagnosis: _____ (0-6) (AJCC Classification, 1988)
Date: ____/____/____
Status of Final Diagnosis: _____ (1-4) Date: ____/____/____
Status of Treatment: _____ (1-4) Date: ____/____/____

C. ATTEMPTS TO CONTACT

Date: ____/____/____ Method: _____ Reason for Contact: _____
Date: ____/____/____ Method: _____ Reason for Contact: _____
Date: ____/____/____ Method: _____ Reason for Contact: _____

PART III. NEW MEXICO TUMOR REGISTRY DATA.

A. DIAGNOSIS. (already on data file)

No cancer-directed surgery: _____
Other Diagnostic Procedure(s) (1) _____ Date Completed: ____/____/____
(2) _____ Date Completed ____/____/____

B. TREATMENT HISTORY.

Site Specific Surgery #1 Type _____ Date Treatment Completed: ____/____/____

Chart Narrative: _____

Facility Code: _____
Physician Code: _____

Site Specific Surgery #2 Type _____ Date Treatment Completed: ____/____/____

Chart Narrative: _____

Facility Code: _____
Physician Code: _____

Site Specific Surgery #3 Type _____ Date Treatment Completed: ____/____/____

Chart Narrative: _____

Facility Code: _____
Physician Code: _____

D. SUBSEQUENT TREATMENTS. Greater than or equal to 4 months. (S, C, R, H, I)

Treatment Type: _____ Code: _____

Date Treatment Initiated: ____/____/____ Date Treatment Completed: ____/____/____

Chart Narrative: _____

Facility Code: _ _ _ _

Physician Code: _ _ _ _

Treatment Type: _____ Code: _____

Date Treatment Initiated: ____/____/____ Date Treatment Completed: ____/____/____

Chart Narrative: _____

Facility Code: _ _ _ _

Physician Code: _ _ _ _

Treatment Type: _____ Code: _____

Date Treatment Initiated: ____/____/____ Date Treatment Completed: ____/____/____

Chart Narrative: _____

Facility Code: _ _ _ _

Physician Code: _ _ _ _

Treatment Type: _____ Code: _____

Date Treatment Initiated: ____/____/____ Date Treatment Completed: ____/____/____

Chart Narrative: _____

Facility Code: _ _ _ _

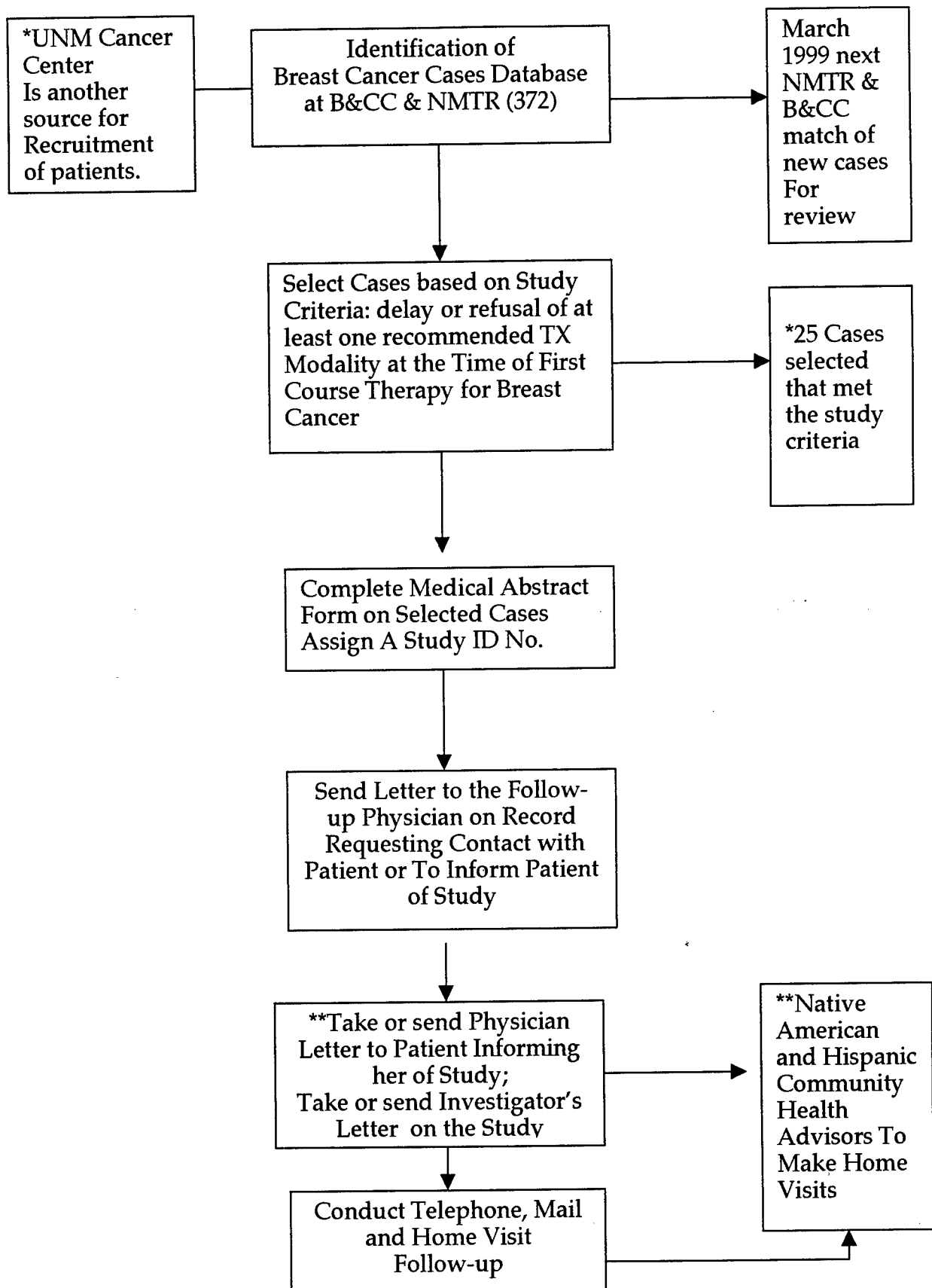
Physician Code: _ _ _ _

Part IV. Abstractor Information

A. Abstracted By: _____ Date This Form Completed: ____/____/____

APPENDIX G.

Patient Identification and Contact Flow Chart



APPENDIX Ga.

Participant Contact Log

ID# _____ / _____ / _____

☐ Discussion/Interview Completed ☐ Tape recorded Discussion Transcribed:

by _____ by _____

date _____ initial _____ date _____ initial _____

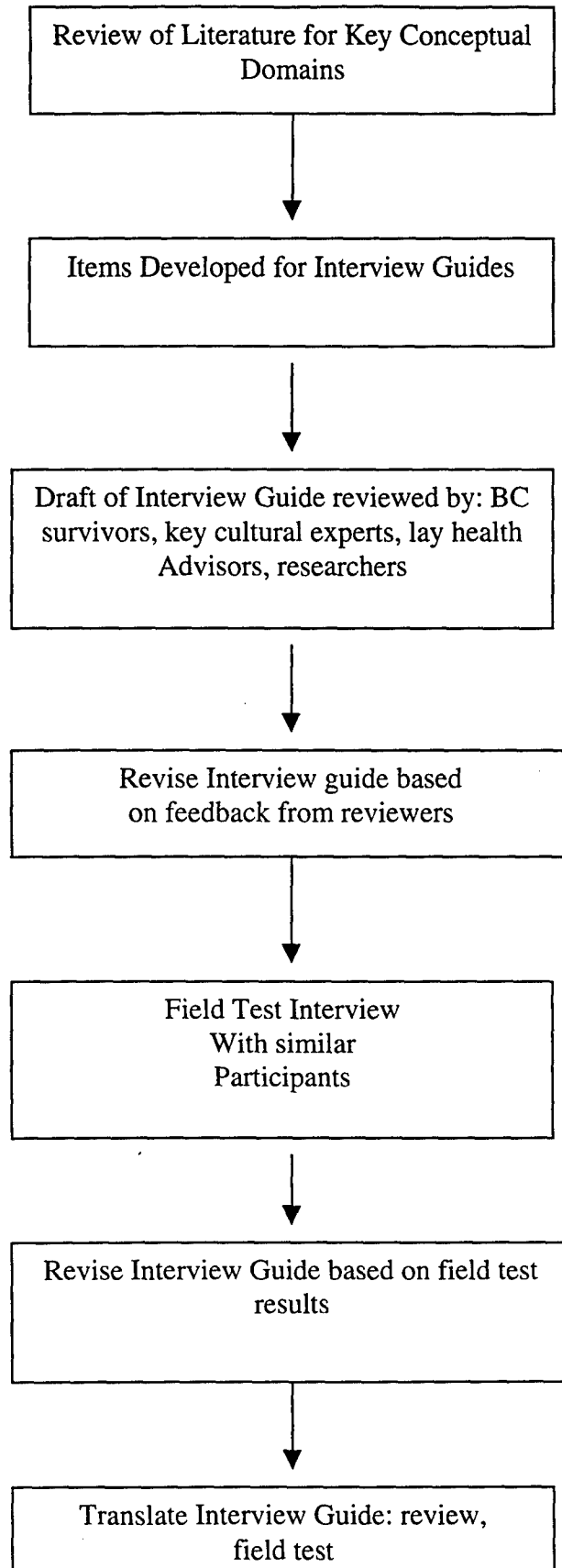
date	time	M/C	I/P	T/C	T/LB	T/LMP	T/LMM	A/C	T/S	F/F	T/I	U/C	R	LTF	COMMENTS	Initials or ID#

M/C= mailed contact letter
 I/P= in person contact
 T/C= telephone contact
 T/LB= telephoned/line busy
 T/LMP= telephoned/left message w/person
 T/LMM= telephoned/left message on machine

T/S= telephone screener completed
 A/C= address changed
 F/F= face to face interview completed
 T/I= telephone interview completed
 U/C= unable to complete (deceased, distressed, ineligible)
 R= refused
 LTF= lost to follow-up

APPENDIX H.

DEVELOPMENT OF INTERVIEW GUIDES



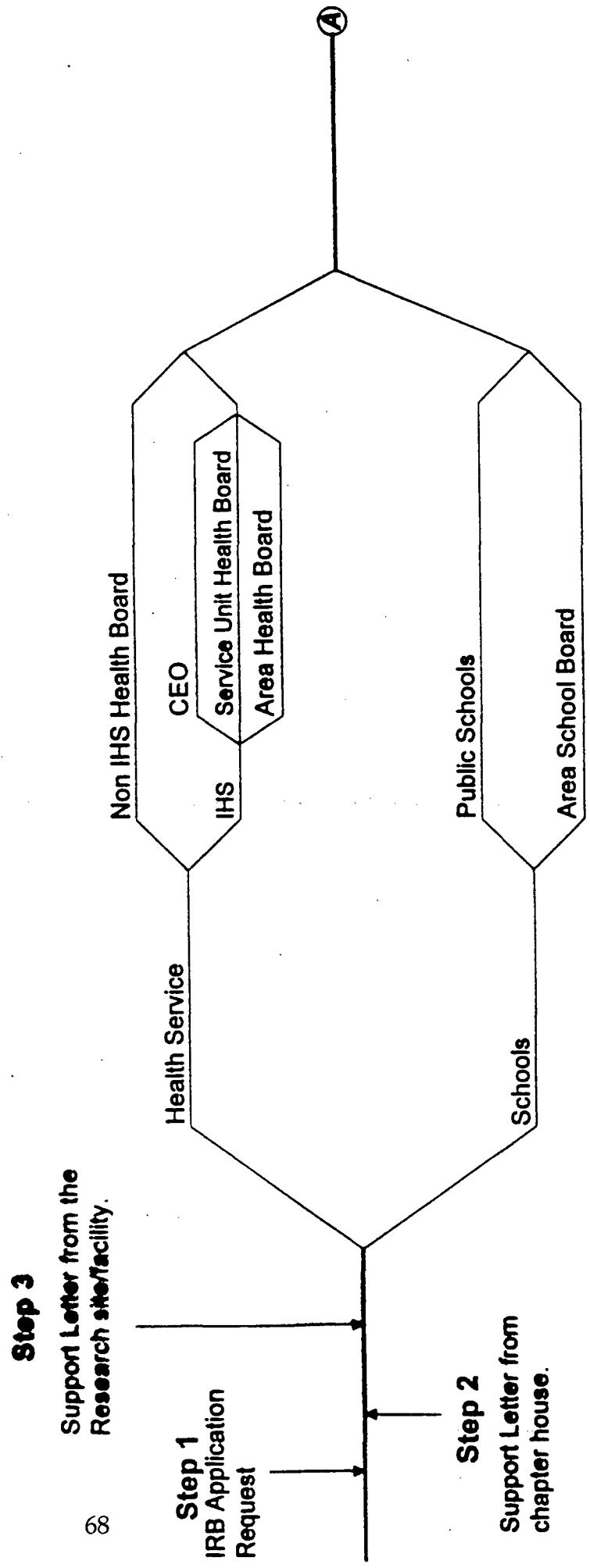
APPENDIX I.

NAVAJO
RESEARCH
PROGRAM

Pre-IRB Review Process

Phase 1

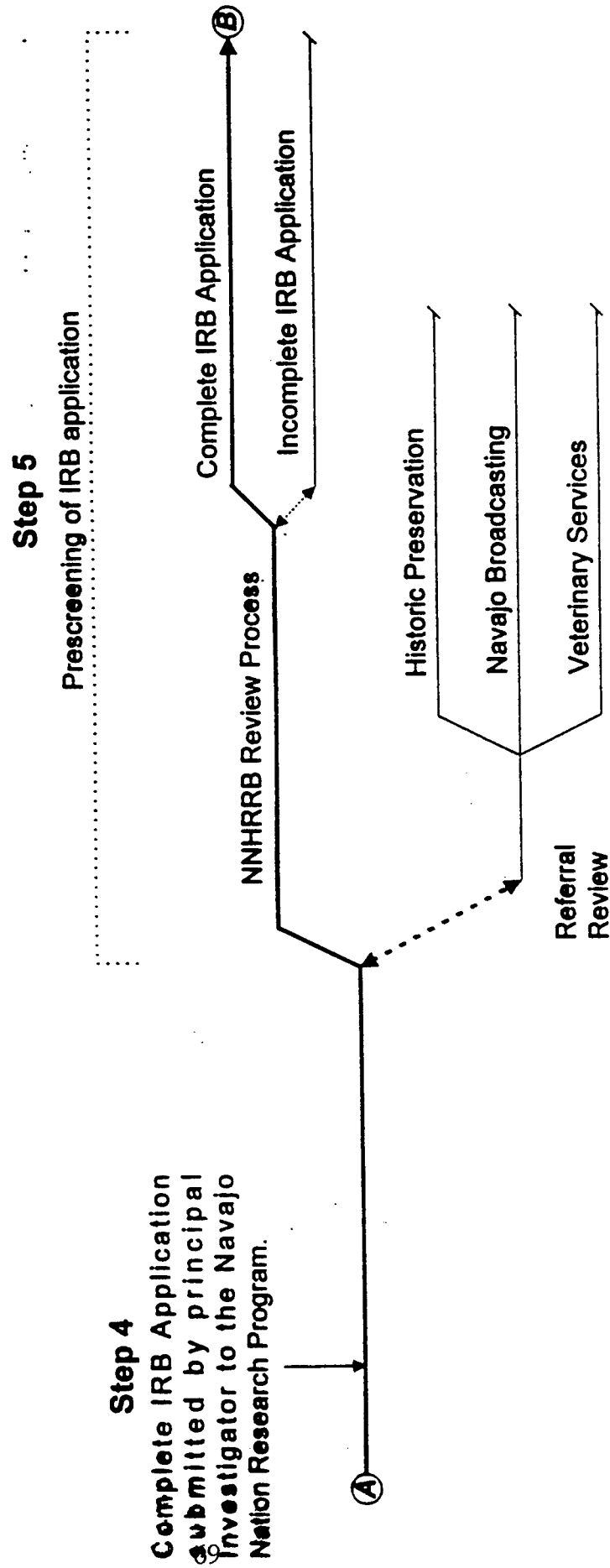
(Community Involvement)



Pre-IRB Review Process

Phase 2

(Pre-screening)

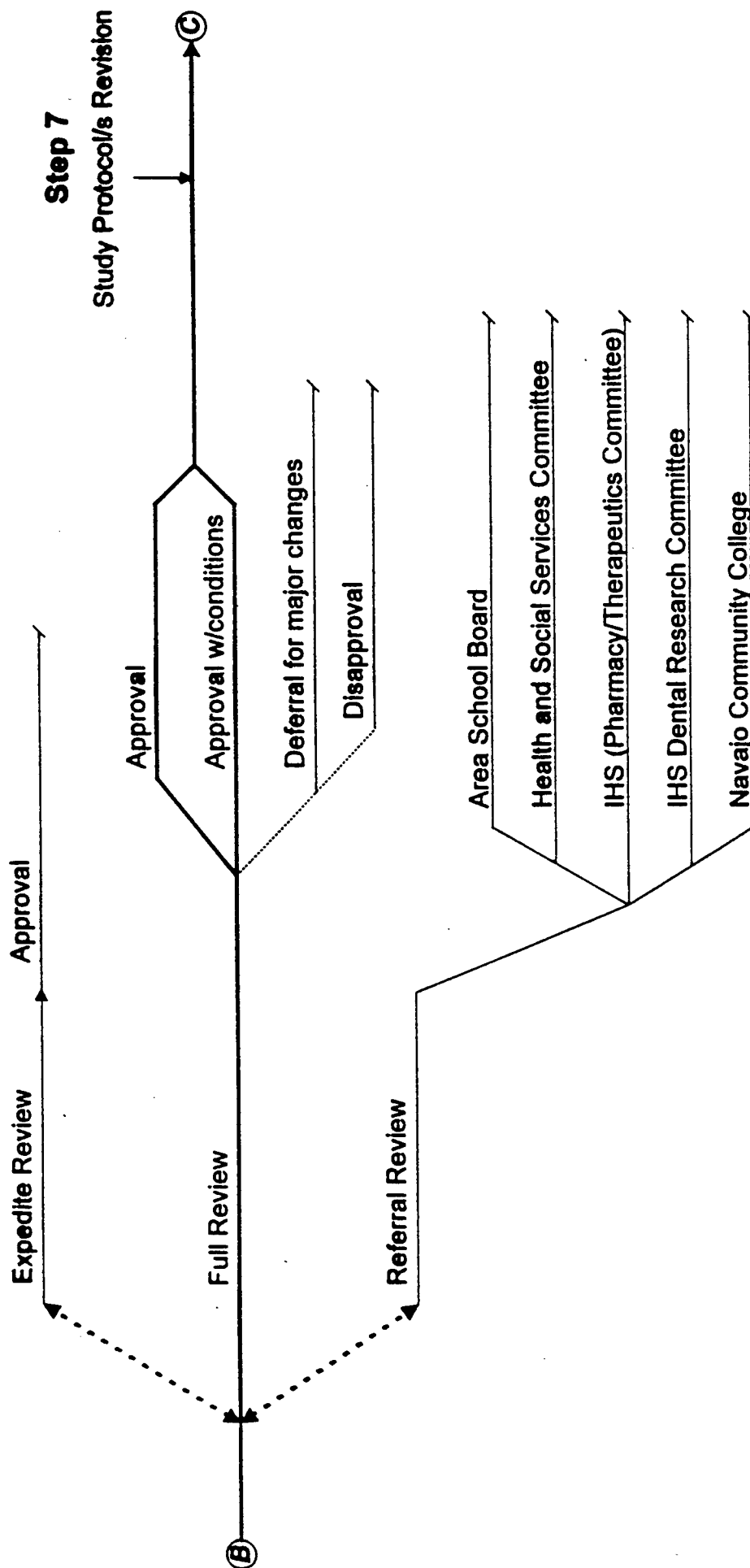


IRB Review Process

Phase 3

(NNHRRB Review)

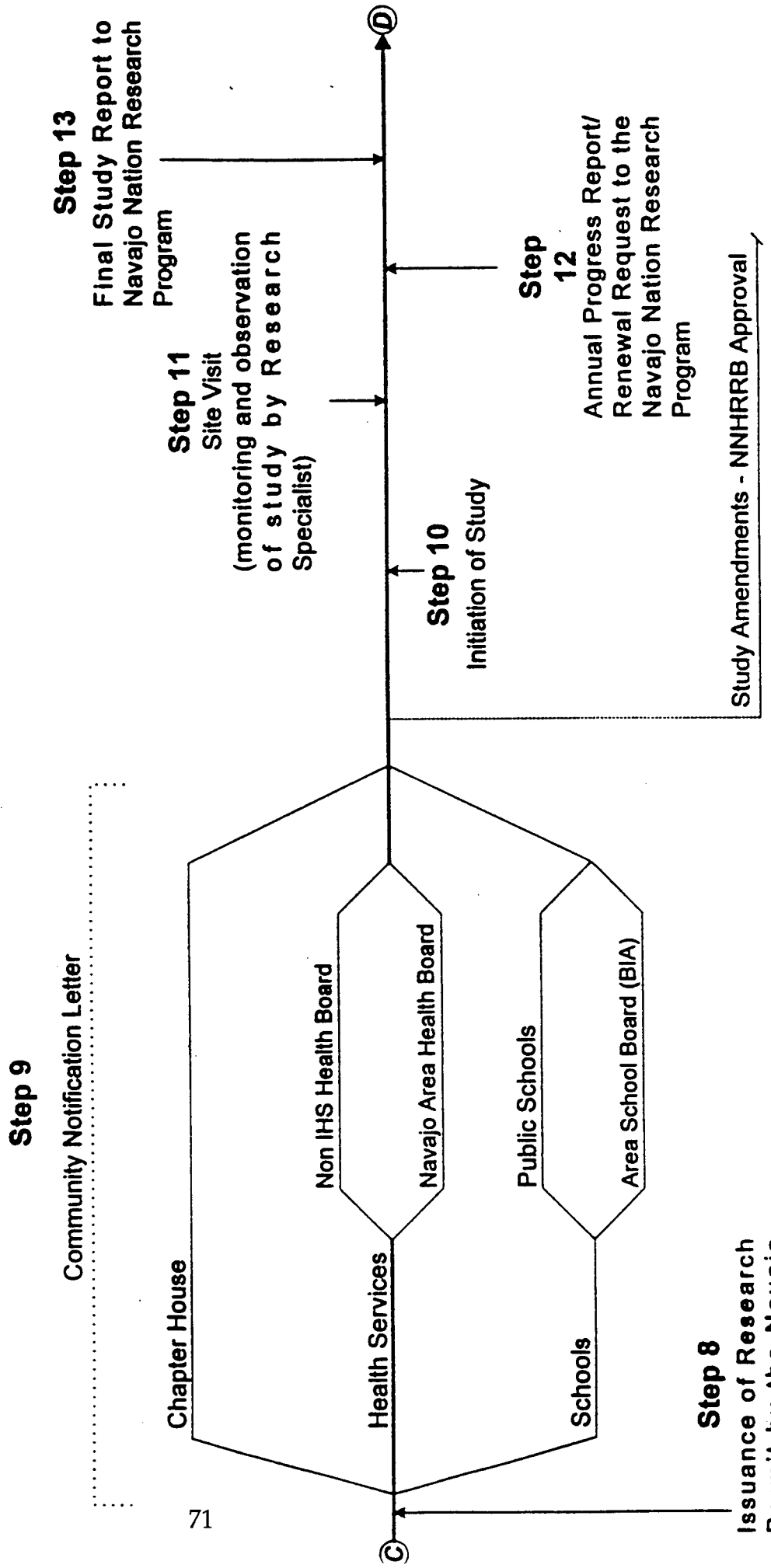
Step 6
Proposal Review by NNHRRB



Post IRB Review Process

Phase 4

(Study)



Post IRB Review Process

Phase 5

(Publication)

Step 16

Submit copies of publication to the Navajo Nation Research Program

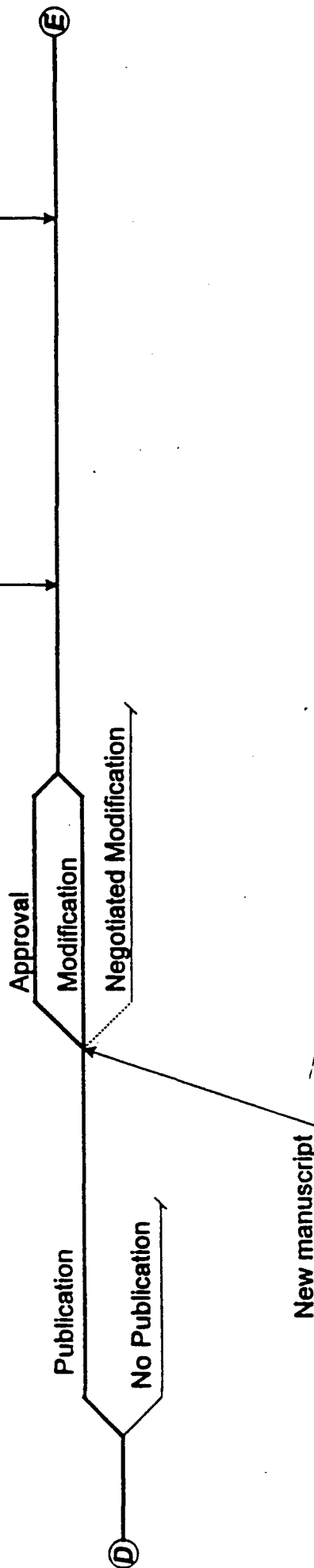
Step 15

Publication

Step 14

Abstract and/or Manuscript Review by NNHRRB

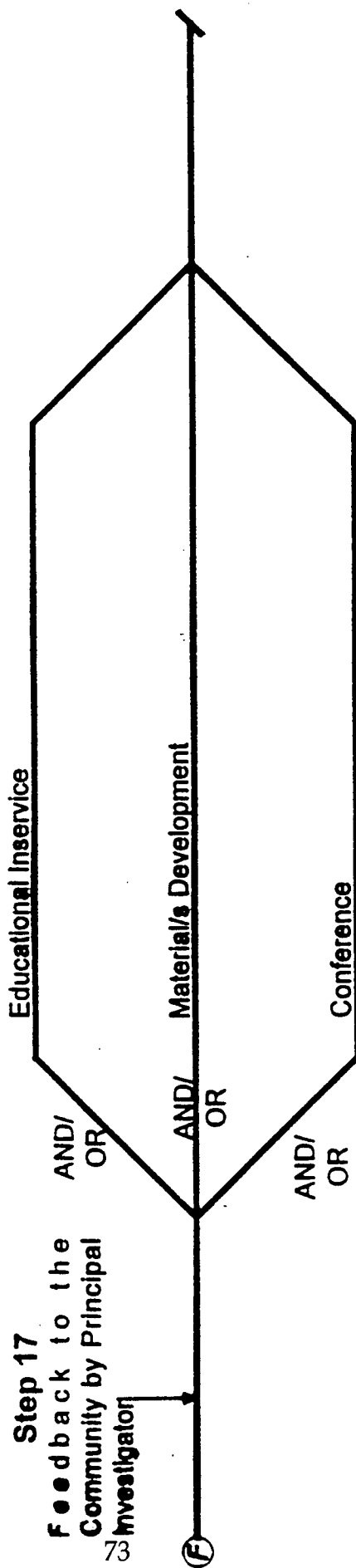
72



Post IRB Review Process

Phase 6

Feedback to the Community



APPENDIX J.

STATEMENT OF WORK (SOW) 1998-1999

YEAR 02 -TIMELINE TASKS												
11-14												
TASK 11 A	Sept	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	June	July	Aug ust
MEETINGS WITH FACULTY MENTORS	COMPLETED											
TASK 11												
(BEGIN INTERVIEWING PATIENTS/FAMILY CAREGIVER -SEE YR. 3) IDENTIFICATION OF PATIENTS THROUGH B&CC/NMTR DATABASE: (SEE APPENDIX D)	COMPLETED											
• Review of 371 records • Completed medical abstract form • Identified 25 potential participants	B&CC/NMTR DATABASE MATCH 371 BC CASES											
TASK 13												
(BEGIN TRANSCRIPTION OF PT & FAMILY INTERVIEWS- SEE YR. 3)												
* Interviews not completed- postponed until Yr. 3												
TASK 13A												
ATTNEDED THE NATIVE WOMEN & CANCER CONFERENCE JAN 8-10 1998 (APPENDIX K)	COMPLETED											
TASK 14	◆◆											
COMPLETE PATIENT INTERVIEWS												
* Interviews not completed- postponed until Yr. 3												
TASK 14A SUBMIT REPORT												
Explanation of Delays with Project Timeline	COMPLETED											
August 1997-												
* In the beginning of Year 02, of project the investigator's mother took ill with renal cell Carcinoma of the left kidney. Ms. Saavedra took time to manage her mother's illness and recovery from illness.												
* In the summer of 1998 Ms. Saavedra underwent surgery and recovery for a painful but benign bone growth in the right wrist.												
* Due to the Navajo Nation's IRB reorganization in 1997, several months of planning, meetings with Navajo Nation IRB were added to project.												
Appendix H	◆◆											

YEAR 03 TIMELINE TASKS 15-22	
TASK 15 • (COMPLETE PATIENT INTERVIEWS) (COMPLETE FAMILY INTERVIEWS)	BEGIN INTERVIEWS COMPLETE INTERVIEWS
TASK 16	
MEETINGS WITH FACULTY MENTORS TASK 17	ONGOING
COMPLETE DATA COLLECTION (NO #18)	TRANSCRIPTION OF PT & FAMILY INTERVIEWS
TASK 19	
COMPLETE TRANSCRIPTIONS	
TASK 20	
CONDUCT ANALYSIS, PREPARE FINDINGS & SUBMIT FOR PUBLICATION	
TASK 21-22	
PRESENT FINDINGS TO FACULTY/NAVAJO NATION. PREPARE AND SUBMIT FINAL REPORT	

APPENDIX K.



Native Women & Cancer CONFERENCE

Doubletree Hotel - Tucson, Arizona - January 8-10, 1998

Sponsored by:

The University of Arizona College of Medicine
Native American Research & Training Center
Department of Family and Community Medicine
at the Arizona Health Sciences Center

THE UNIVERSITY OF
ARIZONA
HEALTH SCIENCES CENTER