ATHEROSCLEROSIS RISK IN COMMUNITIES STUDY

Manual 2

Participant Retention and Follow-Up

Manual of Operations

Version 11.1

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ARIC Coordinating Center

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I. INTRODUCTION

A. BACKGROUND

The Atherosclerosis Risk in Communities Study (ARIC), sponsored by the National Heart, Lung, and Blood Institute (NHLBI) is a prospective epidemiologic study conducted in four U.S. communities. ARIC is designed to investigate the causes of atherosclerosis and its clinical outcomes, and variation in cardiovascular risk factors, medical care, and disease by race, gender, location, and date. To date, the ARIC project has published over 1800 articles in peer-reviewed journals.

The Cohort Component of the ARIC study began in 1987, and each of the four ARIC field centers (Washington County, MD; Forsyth County, NC; Jackson, MS; and Minneapolis, MN) randomly selected and recruited a cohort sample of approximately 4,000 individuals aged 45-64 from a defined population in their community. A total of 15,792 participants received an extensive examination, including medical, social, and demographic data. These participants were re-examined regularly with the first screen (baseline) occurring in 1987-89, the second in 1990-92, the third in 1993-95, the fourth in 1996-98, the fifth in 2011-13, the sixth in 2016-17, and the seventh in 2018-19.

Annual follow-up of the cohort by telephone began in 1987, to maintain contact and to assess health status of the cohort. Beginning in 2012, the cohort is contacted semi-annually.

Objectives of the Study

- Examine the ARIC cohort to characterize heart failure stages in the community, identify genetic and environmental factors leading to ventricular dysfunction and vascular stiffness, and assess longitudinal changes in pulmonary function and identify determinants of its decline.
- Cohort follow-up for cardiovascular events, including CHD, heart failure, stroke, and atrial fibrillation; and for the study of risk factors related to progression of subclinical to clinical CVD.
- Enhance the ARIC cohort study with cardiovascular outcomes research to assess quality and outcomes of medical care for heart failure and heart failure risk factors.
- Provide a platform for ancillary studies, training for new investigators, and data sharing.

B. USING THIS MANUAL

This document serves as the Manual of Operations for ARIC staff who administer the components of the Cohort follow-up interview, and as a reference manual for ARIC staff who perform surveillance activities. Cohort follow-up and surveillance are closely linked within the ARIC study. All cohort members who have CHD or heart failure (HF) related hospitalizations and all cohort deaths are

investigated by surveillance. HF outpatient diagnoses occurring within 3 years of follow-up are investigated by contacting the physician for information to confirm the diagnosis.

High quality of data and a strict standardization of interviews across all field sites and throughout the duration of the study are essential for the success of the ARIC study. This makes it important for all ARIC Field Center personnel to be fully familiar with this manual of procedures. To meet our scientific goals, all ARIC Field Center staff must be fully trained and certified in the procedures described in this manual, and must remain standardized throughout the data collection phase. A complete knowledge of the procedures described in this manual is required so that patterns in the ARIC data can reflect differences between study participants and their characteristics, as opposed to differences between interviewers or deviations from study protocol.

The narrative portion of this manual provides operational information on identifying which and when cohort participants are to be contacted, procedures for initiating and administering the data collection forms in the follow-up interview, linkage procedures between the cohort follow-up and surveillance staff, and a description of the data management system which supports both the Cohort follow-up and the surveillance activities.

Since the inception of the cohort component, the ARIC study has elected to collect a core set of information on its participants, both at its clinical exams and during its annual telephone interviews. For reasons of cost efficiency, it has also been study policy to add or remove items which reflect expanding areas of research interest or information that does not require annual data collection. Several of the core data collection elements from the clinical exams were transferred to the annual telephone interviews.

Recent versions of the follow-up form allowed ARIC interviewers more formally and systematically to identify proxies for ARIC cohort members who are unable to provide the information ascertained during the follow-up interview. In 2012, cohort telephone follow-up changed from annual to semi-annual to obtain more reliable information on clinical events and outcomes measures. The semi-annual interview is comprised of several forms that capture the content of the annual follow-up as well as new content in a general interview instrument. The questions on the general interview instrument (which changes yearly) address the participant's physical ability and health care services status. The cohort will be followed by phone calls to obtain information about medical care, along with medical records abstraction and linkage to Centers for Medicare Services (CMS) data, to evaluate patterns of self-care and treatment, elucidate factors contributing to those patterns, and assess short and long term outcomes.

II. RETENTION AND FOLLOW-UP OF COHORT MEMBERS

A. INTRODUCTION

Follow-up of cohort members is used to:

(1) maintain contact and correct address information on ARIC cohort participants;

(2) update tracing information on up to three contact persons;

(3) ascertain the participant's vital status; and

(4) document general health, medical events, hospitalizations, life events, and functional, socio-economic, and smoking status since the last contact with ARIC staff. Table 1 provides a summary of follow-up data collected.

There are five primary components in this process:

(1) the generation of scheduling material by the ARIC field centers;

(2) the scheduling of the follow-up interview by Field Center staff and the administration of the follow-up interview which includes the ascertainment of medical information relating to hospitalizations for cardiovascular disease and documentation of fatal events;

(3) the review of hospitalization information collected during the follow-up interview to determine whether additional diagnostic or abstracting procedures are required in hospital medical records;

(4) the transfer of information obtained during the follow-up interview to the surveillance staff; and

(5) contact of physicians for information on outpatient HF diagnosis. These steps are summarized in Table 2 and described in the following sections.

Table 1. Summary of Data Collected During Cohort Follow-up Interview from ARIC Cohort Members

	A	B	C	D	E	F	G	H	I	J	K	L	M	V1	V2	V3
DATE OF STATUS DETERMINATION	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
VITAL STATUS	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
DATE OF DEATH	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
LOCATION OF DEATH	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
COMPARISON OF HEALTH TO OTHERS ONE'S OWN AGE	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
CHEST PAIN ON EFFORT (Rose questionnaire)	X	X	X	X	X	X										
POSSIBLE INFARCTION	X	X	X	X	X	X										
INTERMITTENT CLAUDICATION (Rose questionnaire)	X	X	X	X	X	X										
STROKE/TIA	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
HOSPITALIZATIONS	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
FUNCTIONAL STATUS				X	X	X	X	X	X	X	X					
WEIGHT LOSS > 10 POUNDS IN PAST YEAR				X	X	X										
MARITAL STATUS				X	X	X	X	X	X	X	X	X	X	X	X	X
DEATH OF SOMEONE CLOSE				X	X	X										
RESIDENCE WITHIN ARIC STUDY BOUNDARIES						X	X	X	X	X	X	X	X			
NURSING HOME ADMISSIONS							X	X	X	X	X	X	X	X	X	X
HISTORY OF CARDIOVASCULAR AND RELATED DISEASES							X	X	X	X	X	X	X	X	X	X
DIAGNOSTIC PROCEDURES FOR CVD							X	X	X	X	X	X	X	X	X	X
INVASIVE PROCEDURES/ TREATMENT FOR CVD							X	X	X	X	X	X	X	X	X	X
CURRENT MEDICATIONS FOR HYPERTENSION, HIGH CHOLESTEROL, DIABETES							X	X	X	X	X	X	X	X	X	X
REGULAR OR CURRENT USE OF ASPIRIN							X	X	X	X	X	X	X	X		
HISTORY OF HRT USE OR GYNEGOLOGIC SURGERY							X	X	X	X	X					
CURRENT CIGARETTE SMOKING							X	X	X	X	X	X	X	X	X	X
CURRENT EMPLOYMENT STATUS							X	X	X	X	X					
AVAILABILITY OF MEDICAL RECORDS THROUGH COMMUNITY SURVEILLANCE							X	X	X	X	X	X	X			

INVESTIGATE HISTORY OF OUTPATIENT HF/CHF												X	X	X	X	X
HISTORY OF ATRIAL FIBRILLATION,												X	X	X	X	X
SWELLING FEET OR ANKLES												X	X	X	X	X
LUNG DISEASE												X	X	X	X	X
BREATHING PROBLEMS												X	X	X	X	X
HISTORY OF ASTHMA												X	X	X	X	X
HISTORY OF PAD OR INTERMITTENT CLAUDICATION												X	X	X	X	X
PRESCRIBED MEDICATIONS												X	X			
CANCER															X	X

Table 2. Components of Cohort Follow-up

Generation of Scheduling Materials	Participant Contact	Forward Information to Surveillance Staff	Act on Information Provided by Cohort Staff	Contact Physician for information on HF diagnosis if less than 3 years from AFU date
Generate participant contact lists; send pre-follow-up interview letters.	Contact participant or informant by phone; document participant's vital status; administer AFU interview; update tracking information; update informed consent if requested by participants.	Transfer vital status and hospital discharge information to Surveillance staff.	Review hospitalizations from interview; perform additional diagnostic procedures; abstract discharge summaries and medical records when indicated.	Obtain permission from the participant to send the physician the PHF Questionnaire to give the information regarding the HF diagnosis. Enter the PHF form in DES once received. This began in the fall of 2006 with AFU.

B. Eligibility Requirements for Follow-up Interviews

Participants who completed at least part of the baseline examination (Visit 1) have been contacted annually since Visit 1. Individuals excluded from annual follow -up were only those enumerated residents who completed the home interview, but did not sign the informed consent form at the first Field Center examination (Visit 1).

Unless deceased or requested otherwise by the participant to withdraw consent for follow-up, an attempt is made to contact all ARIC cohort members regardless of whether they continued after Visit 1 to participate in Field Center examinations or missed a given contact year's (CY) interview. This includes participants who have a designated proxy and those who have moved away from the community in which they were recruited. Telephone follow-up interviews can be conducted anywhere in the continental U.S. and other countries. Addresses and telephone numbers of cohort members with multiple residences are kept on file to contact participants on their target date.

C. PROXY RESPONDENTS FOR ARIC COHORT MEMBERS

For purposes of the ARIC follow-up call, a proxy is defined as a well-informed individual who can answer health related questions on behalf of an ARIC cohort member. In most cases the ARIC proxy is/has been designated by the ARIC cohort member at the request of ARIC personnel. If the ARIC participant is not in a position to designate a proxy, ARIC attempts to contact a next-of-kin (spouse, son or daughter, brother or sister to identify a proxy. In this process it is important to identify a person who is well informed and trusted by the ARIC participant, since this may include partners and close friends. A proxy initially designated by the ARIC study participant may designate another individual as proxy if better informed or able to serve that role. Also to accommodate changing circumstances, a designated power of attorney or health care power of attorney may serve as proxy even if not identified as such when the study participant was able to make this decision.

The proxy may be able to authorize the release of medical records should the participant be unable to do so. If it is established that a power of attorney, or a Legal Health Care Proxy has been designated, this person should be contacted to sign a request for release of medical records. Medical records departments may request a copy of the Power of Attorney.

Role of a Proxy

The role of a proxy can be different from an informant and that of a contact person. An informant (also called proxy informant) typically assists the participant in responding to an ARIC interviewer but do no act or respond on behalf of the ARIC participant. Informants may enable the interview by assisting a cohort member with hearing difficulties, or even help the participant locate items or remember needed information. If instead the role of the informant is to supplement the participant's recall or the ability to respond the interview, a transition into interviews by proxy must be considered. As mentioned below, the use of the Six Item Screener is recommended in these circumstances.

A contact is a person ARIC was referred to by the cohort member as somebody who keeps track of the location and/or activities. The contact can assist ARIC in locating a study participant or in ascertaining their hospitalization or vital status. Contacts can be relatives, a friend, or a close neighbor. During an ARIC interview a contact is not asked to respond on behalf of a study participant. Section A.1 of the follow-up interviews (AFU/SAF) identifies information obtained via a proxy or informant, as individuals designated by the study participant and stored in the ARIC database. Item A.1 (Result of contact for the Interview) also has an entry for 'other person contacted', to indicate persons previously listed by the cohort member as a contact (not a proxy), or identified by ARIC personnel in the process of tracing a cohort member they have been unable to locate.

In conducting an annual or semi-annual interview with a respondent who is not the cohort member, ARIC attempts to learn as much information as seems reliable about hospitalizations, approximate dates and location of the hospital or ER, medical procedures, cardiovascular events, fatal events, and the corresponding dates. The General Health questions (Item C of the AFU) are not administered to

respondents other than the study participant. Item D questions (Cardiovascular Events) are asked of all respondents. The Medical Conditions Update (MCU) form also identifies sections to be administered (only) to study participants and those for participants or their proxy/informant.

Conducting an Interview with a Proxy

When an interview is completed by a proxy, the proxy is asked to answer for the participant (to the best of his/her knowledge) instead of the participant responding him/herself with the help of the "proxy." If the proxy does not know the answer, "Unknown" is recorded rather than a guess. During the interview the participant's name or "him/her" should replace "you" in the specific questions, where appropriate. An interview completed by a proxy is recorded as directed in the follow-up form QxQ.

When is a Proxy Needed?

If the interviewer has indications that the participant may have cognitive difficulties the interviewer uses his/her judgment to determine if the participant is cognitively impaired and unable to answer questions reliably, and should use the Six Item Screener (SIS) to assist in making this determination. If the interviewer is unsure or unwilling to make this determination, the Supervisor should be contacted before proceeding with the interview.

Through interaction with the participant (or because a proxy was engaged in a previous follow-up interview) the ARIC interviewer determines whether the participant has the ability to respond. Because the criteria that trigger the use of a proxy are subjective, the follow-up interviewers are trained in the use of the Six Item Screener (SIS) to assist in making this decision. Failing the Six Item Screener (a SIS form coded as Impaired) indicates the need for a proxy interview to be scheduled for the follow-up contact for this study participant. Similarly, if the last SIS assessment was listed as 'Not Scored' the next contact for this cohort member should be scheduled with his/her proxy (the SIS is not scored when the SIS was not attempted (SIS1=No) or 3 or more questions on the SIS are missing responses). Having a failing score (Impaired) on the ADS form (AD8 screener) also indicates the need for subsequent follow-up contacts to be scheduled with the proxy.

Before scheduling a follow-up interview, ARIC personnel determines the above conditions and whether the previous follow-up interview was conducted with a proxy, in order to contact him/her to schedule the call. Other criteria available to the interviewer to determine whether a proxy is needed are a self-report of hearing problems or cognitive impairment.

Identification and Tracking of the Proxy

ARIC Field Center staff has systematically requested that each cohort member identify a proxy, or proxy informant, and has recorded the designated proxy and his/her contact information. An important element of each follow-up interview includes asking participants to update the information on a proxy who is able to answer questions about the participant's health if he/she is unable to provide that information themselves. This information is collected on the Contact Information Update (CIU) form.

When are Interviews with a Cohort Member Discontinued?

When certain milestones have been met indicating that a study participant is severely cognitively impaired ARIC discontinues interviewing the participant or the proxy/informant. This is referred to discontinuation of dementia surveillance and is presented in ARIC Manual 20 – Dementia Surveillance.

D. TIME WINDOW FOR FOLLOW-UP CONTACTS

1. ANNUAL FOLLOW-UP CONTACTS

The TARGET date for the Annual Follow-Up interview is the Visit 1 anniversary date for the given contact year. The EARLIEST date is 3 months before the TARGET date and the LATEST date is 3 months after the TARGET date. Phone interviews can take place no sooner than the earliest date and no later than the latest date. Three key dates defining when the participant is to be contacted are provided on the Participant Tracing Report.

Example: Participant X had a visit 1 date of July 1, 1988

The window for his annual follow-up interview is April 1 through October 1, with a target date of **July 1**.

2. SEMI-ANNUAL CONTACTS

The TARGET date for the Semi-Annual Follow-up interview is the date 6 months following the Visit 1 anniversary date for the given contact year. The EARLIEST date is 3 months before the TARGET date. The LATEST date is 3 months after the TARGET date. Phone interviews can take place no sooner than the earliest date and no later than the latest date. Three key dates defining when the participant is to be contacted are provided on the Participant Tracing Report.

Example: Participant X had a visit 1 date of July 1, 1988

The window for his semi-annual follow-up interview is October 1 through April 1, with a target date of **January 1**.

Table 3. ARIC Contact Years and Corresponding Calendar Years

Calendar Year	Baseline year 1987	1988	1989
	Visit 1		
(86)			
1987	**CY01**	--	--
1988	CY02	**CY01**	--
1989	CY03	CY02	**CY01**
	Visit 2		
1990	**CY04**	CY03	CY02
1991	CY05	**CY04**	CY03
1992	CY06	CY05	**CY04**
	Visit 3		
1993	**CY07**	CY06	CY05
1994	CY08	**CY07**	CY06
1995	CY09	CY08	**CY07**
	Visit 4		
1996	**CY10**	CY09	CY08
1997	CY11	**CY10**	CY09
1998	CY12	CY11	**CY10**
(99)			
	Post Visit 4		
1999	CY13	CY12	CY11
2000	CY14	CY13	CY12
2001	CY15	CY14	CY13
2002	CY16	CY15	CY14
2003	CY17	CY16	CY15
2004	CY18	CY17	CY16
2005	CY19	CY18	CY17
2006	CY20	CY19	CY18
2007	CY21	CY20	CY19
2008	CY22	CY21	CY20
2009	CY23	CY22	CY21
2010	CY24	CY23	CY22
	Visit 5		
2011	CY25	CY24	CY23
2012	CY26	CY25	CY24
2013	CY27	CY26	CY25
	Post Visit 5		
2014	CY28	CY27	CY26
2015	CY29	CY28	CY27
	Visit 6		
2016	CY30	CY29	CY28
2017	CY31	CY30	CY29
	Visit 7		
2018	CY32	CY31	CY28
2019	CY33	CY32	CY31
2020	CY34	CY33	CY32

E. PARTICIPANT RETENTION

One of the challenges of recurring interviews is falling response rates. Non-response is made up of refusals and non-contacts. As our study population grows older, it can become more difficult to contact participants and more challenging to complete interviews. Increasing survey length and interview requests may also make it less likely that participants will agree to interview and perhaps less likely for them to be able to complete the interview. Retention of follow-up participants is essential to the continued success of the ARIC study. When response rates fall low enough, questions about the representativeness of the respondents are raised. The most serious consequence of interview nonresponse is that the collected data can be biased, if the answers of participants differ from the potential answers of those who did not participate. As contact rates and response rates fall, centers should consider a range of techniques to increase contact and participation.

Tools used to retain follow-up participants include: periodic newsletters, Field Center websites, birthday or greeting cards, and holiday or end-of-year cards. Documents and content created for participants should be at an appropriate reading level and designed to be culturally and religiously appropriate. Proxy respondents should also be considered for participants who are no longer able to complete an interview. In addition, identification and utilization of interviewers who are especially successful in retaining participants should be considered during training. More experienced interviewers tend to achieve higher response rates than less experienced interviewers. Effective strategies for retaining participants should be shared, and interviewers trained in effective techniques for addressing the concerns and objections of participants.

Interviewer factors that can increase response include motivation and training (especially in overcoming objections) and more call attempts. This area is addressed in greater detail in Section II.H.

F. PREPARATION FOR FOLLOW-UP INTERVIEWS

Field centers initiate the follow-up procedures by generating the Participant Tracing Report and the Participant Tracing Sheet from the cohort database. The participant tracing report lists all cohort IDs that are to be contacted for follow-up interview in a given time frame. The Participant Tracing Report has an option to allow printing of a "Record of Calls" to track attempts to contact the participant. The Participant Tracing Sheet provides detailed, confidential information for individual participants including address, date of birth, Social Security Number (optional), driver's license number, contact persons, Visit dates, and contact status at the most recent annual (or semi-annual) interview. Data security procedures that apply to confidential information must be in place to access, store, transport and dispose of these reports. It is each field center's responsibility to comply with the HIPAA regulations and its Institution's data security policy in handling and/or processing data with personal identifiers and PHI.

In preparing for the follow-up call, the interviewer reviews the information presented on the tracing sheets to determine the date of last contact, and whether this date corresponds to an interview with the participant, a contact or a proxy, or whether the participant could not be reached during the previous contact window.

If the information on date of last contact presented on the tracing sheets indicates that neither the participant nor a proxy could be reached during the previous contact window, the actual date of last contact is used during the current interview to identify the occurrence of ARIC study outcomes (health events, hospitalizations, revascularizations, etc.). This applies to items that ask the participant (or the proxy) "Since we last contacted you [name] on [mm/dd/yy] has a doctor said that …" and it also applies to deceased cohort members (e.g. "Was [name] hospitalized for a heart attack, or heart condition, or stroke since our last contact on [mm/dd/yy]?"). Thus, health outcomes are ascertained with reference to the last actual contact, even if it occurred before the previous contact window.

All participants who cannot be contacted by phone are sent this letter on ARIC study stationery as a reminder and "forwarding and address correction requested" is stamped on the envelope. Participants who do not have phones, have trouble communicating by telephone, or have special needs are not contacted by telephone but are visited in person. If these participants can be identified in advance, the letter indicates that an interviewer will call and schedule a visit to the home, extended care facility, etc., and the follow-up interview takes place there.

Participants found to have moved or who are otherwise lost to follow-up are traced using the tracing information obtained at Visit 1 and during subsequent follow-up contacts or from other local sources of information, such as the telephone directory, city directory, etc. By using the Participant Tracing Sheet and possibly the CIU (Contact Information Update) form, Field Center staff can call or write to the family members, friends, , or physicians the participants identified as contact persons during previous interviews. By using social security numbers, periodic searches of the National Death Index are done. Every attempt is made to schedule and complete an AFU interview for each participant.

Follow-up interviewers telephone study participants at their homes at optimal times (i.e., late afternoons, evenings, or weekends) to conduct the follow-up interview. When the timing of the initial contact is inconvenient for the participant, the interviewer reschedules the follow-up interview. When a cohort member cannot be reached on the first call, the interviewer documents the contact status as directed, and makes return calls as necessary, at varying times of the day and week until either the participant is contacted or the scheduling window for interview is closed. A final contact status (result of contact for the interview) code indicating unable to contact is only assigned after all avenues have been exhausted and Supervisor approval has been obtained. Experience has shown that participants who are lost to follow-up in one year may be located in subsequent years of follow-up and only participants who die or insist on no further contact with the ARIC study should be considered irreparably lost to the study.

G. General Instructions for Conducting Follow-up Interviews

The participants' responses are entered onto the Data Management System directly, or recorded on the paper versions of the forms for delayed data entry into a data management system housed and maintained by each ARIC study center. The follow-up forms, and the QxQ instructions for administering the follow-up forms are provided on the ARIC website.

Refer to the ARIC website for the most current versions of all annual and semi-annual follow-up forms and QxQs: https://www2.cscc.unc.edu/aric/annual-follow-up-forms

1. Annual Follow-up

Annual follow-up of the ARIC Study cohort is used to maintain contact and correct address information of cohort participants, ascertain vital status, document interim medical and life course events, and memory and attention problems which have occurred since the last contact.

The interview target date for the annual follow-up call is the participant's Visit 1 anniversary date.

The annual interview target date has a 3-month scheduling window before and after the target date. These scheduling windows allow for flexibility to accommodate the study participant's preferences, unanticipated absences or illness. ARIC protocol requires study personnel to adhere to the target dates in scheduling the follow-up interviews, to the degree possible. Scheduling the annual calls earlier than the target window or later can only be done to accommodate study participant needs.

If the participant is contacted and agrees to be interviewed, four forms are routinely completed during the annual follow-up (AFU) interview: the AFU Questionnaire (AFU), the Medical Conditions Update Form (MCU), Six Item screener (SIS)-see manual 20 for protocol on collecting (or ADS if speaking with proxy), and the Contact Information Update Form (CIU), formerly the UPD - Update Form. Follow-up proxy information is collected on the Contact Information Update Form (CIU).

Two other forms may be completed during the AFU interview. If during the course of the AFU interview a participant requests a change in his or her consent level, i.e., use/storage of DNA, use of other study data, access to medical records, or withdrawal from the study, the Informed Consent Tracking (ICT) form is also completed. Note that the ICT form can be completed any time a participant requests a change in consent even if this does not occur during the AFU phone call (see QxQ for ICT form).

Interviewers may also need to request authorization to contact the participant's physician for information on selected health problems, additional to that reported by the participant during the AFU interview. When the participant reports that he/she has been diagnosed as having heart failure (HF) by a physician during the time frame specified in the AFU, the interviewer initiates the process that enables ARIC to send that physician a request to complete the Physician Heart Failure Survey Form (PHF).

The usual form completion flow for the Annual Follow-up is:

- Participant alive
  - Participant contacted
    - AFU – SIS – MCU – CIU
  - Proxy/Informant/Other person contacted
    - AFU – ADS – MCU – CIU
- Participant deceased
  - Proxy/Informant/Other person contacted
    - AFU - DEC – ADS – CIU

2. *SEMI-ANNUAL FOLLOW-UP*

Semi-annual follow-up of the ARIC Study cohort is used to maintain contact and update address information of cohort participants, ascertain vital status, document interim medical and life course events that occurred since the last contact, and obtain information about medical care.

Semi-annual follow-up contacts should be scheduled once a year, to take place between annual follow-up interviews. The target date for the semi-annual interview is 6 months following the annual contact target date.

The semi-annual interview target date has a 3-month scheduling window before and after the target date. These scheduling windows allow for flexibility to accommodate the study participant's preferences, availability and/or illness. ARIC protocol requires study personnel to adhere to the target dates in scheduling follow-up interviews, to the degree possible. Scheduling the semi-annual calls earlier than the target period or later can only be done to accommodate study participant needs.

If the participant is contacted and agrees to be interviewed, three forms are routinely completed during the semi-annual follow-up interview: the semi-annual follow-up Core Questions (SAF), the Medical Conditions Update Form (MCU) and the General Interview and the Contact Information Update Form (CIU) is updated. If the participant is unable to answer questions about his/her health and a proxy/informant or other person is contacted, only the semi-annual follow-up Core Questions are completed during the interview. The Death Information (DEC) is completed in addition to the semi-annual follow-up core questions in the event that the proxy/informant reports that the participant is deceased.

If during the course of the SAF interview, a participant requests a change in his or her consent level, such as access to medical records, use, storage or sharing of genetic material, or withdrawal from the study, the Informed Consent Tracking (ICT) form is also completed. Note that the ICT form can be completed any time a participant requests a change in consent even if this does not occur during an annual or semi-annual phone call (see QxQs for the ICT form).

As part of the SAF interview, it may also be necessary to request authorization to contact the participant's physician for information on selected health problems, additional to those reported by the participant. When the participant reports that he/she has been diagnosed as having heart failure (HF) by a physician during the time frame specified in the SAF, the interviewer initiates the process that enables ARIC to send the physician a request to complete the Physician Heart Failure Form (PHF).

The usual form completion flow for the Semi-Annual Follow-up is:

- Participant alive
  - Participant contacted
    - SAF – GEN* – MCU – CIU
  - Proxy/Informant/Other person contacted
    - SAF – MCU – CIU
- Participant deceased
  - Proxy/Informant/Other person contacted
    - SAF - DEC – ADS – CIU

*General Interview Form (GEN) is revised yearly

H. INTERVIEWING TECHNIQUES

The goal of data collection by interviewing is the collaborative acquisition of epidemiologic data, using standardized techniques at each examination site for the duration of the study.

1. INTERVIEWER BIAS

The use of rigidly, standardized interviewing techniques is employed to reduce one of the many potential sources of misclassification; i.e., interviewer bias, a *systematic* difference between responses obtained by different interviewers. Although introductory scripts may be modified to respond to different situations an interviewer may encounter scheduling the follow-up interview, administration of each question exactly as worded and use of standardized definitions or explanations are critical.

2. CHARACTERISTICS OF A GOOD INTERVIEW

Interviews are friendly but businesslike. At the beginning of each encounter the interviewer makes introductions and verifies the participant's name. Participants are always thanked at the conclusion of interview sessions. Interview areas should be as quiet and private as possible. Although this is often out of the control of the interviewer, participants should be encouraged to reschedule their interviews at a time when these conditions are possible.

Interviews are the structured, one-sided passing of information, not a conversation. The pacing of questions is based on the comfort and comprehension of the participant with each interview; it may vary as the content, complexity or period of recall of the person or subject matter changes. During an interview, questions from the participant are answered with neutral, nonjudgmental responses: questions to the participant are limited to probes to clarify or resolve incomplete, ambiguous or inconsistent responses; repeating a question is most appropriate when the participant does not appear to understand the intent or meaning of the question. Gently stressing the portion of the question which was not understood when the question is repeated (e.g., "has a doctor ever") is often more efficacious that rereading it in exactly the same manner.

3. CHARACTERISTICS OF A GOOD INTERVIEWER

Interviewers are responsible for being familiar with the questions, response categories and skip patterns of each interview. In the role of a telephone interviewer, the Field Center staff member thinks [acts?] as an interviewer, an impartial collector of data, and not, for example, as a clinician, investigator, friend or neighbor. Interviewers use a conversational tone and establish a pace consistent with the interest and ability of the participant. A good interviewer projects the importance of the interview to the participant and attempts to gain his/her confidence, while remaining impartial and nonjudgmental. For example, a verbal response (or body language when the interview is being conducted in person) which indicates positive feedback is always inappropriate, even in the light of

participant reports of behavioral modifications which in a clinical setting would result in praise and encouragement. Participant confidence in the confidentiality of each response/measurement is established.

4. *COMMUNICATION TRAPS*

Communication traps include: (1) anticipating or answering questions directed to the participant with the interviewer's own thoughts; (2) hearing what one expects to hear; or (3) being drawn into a conversation. The putative sensitivity of a question is often as much a perceptual problem of the interviewer as it is the participant. Questions thought to be "sensitive" should be asked in a neutral manner which does not differ from the normal professional flow of the interview.

5. *CONDUCTING THE INTERVIEW*

Many interviews require the interviewer to train the respondent. During a telephone interview this has to be done by verbal instructions. For example, responses may follow a series of patterned questions, e.g., a doctor diagnosed condition, age at onset, and age at treatment during the participant's lifetime or may require the selection of the most appropriate category from a series of descriptors, e.g., almost never, sometimes, often and almost always. These instructions should be repeated until it is clear that the respondent understands them, and then subsequently offered only as needed.

The most important technique for conducting a rigorously standardized interview is to read the question in the exact words and in the exact sequence as printed in the questionnaire. When questions are to be asked out of the printed sequence, a skip instruction is printed on the form. Every question must be asked, even if the participant appears to have provided the information in the answer to another question.

Reading the transition statements exactly as they are worded is equally important in maintaining standardization. The transition statements are designed to inform the participant about the nature of a question or a series of questions, to define a term, establish a time frame or describe what is being asked in the question. This is particularly important in this version of the AFU form. Most of the questions are familiar to the ARIC participant, either from previous AFU interviews, or from participation in the clinic visits. However, the time frames for these questions are frequently different from those that were in a previous section of the AFU, or different from those that were administered during a previous interview.

Response styles of an interviewer influence the willingness of the participant to respond to questions and the quality of the response. Inappropriate styles include those that are evaluative or judgmental, interpretive or pedantic. Interrupting responses for reasons other than to focus or channel the participant's answer is counterproductive.

Appropriate styles of interviewing include providing supportive noises to reassure, pacify or reduce the intensity of the respondent's feelings. These include general clucking or an understanding murmur. Nondirective or understanding statements, such as a repetition of what the respondent has just said (in contrast to paraphrasing), reassure or show interest without intruding on the flow of the response.

Probing is appropriate to seek further information, provoke further discussion along a certain line of thought or explanation, or to question the respondent. In general, and unless specifically countermanded in the QxQ instructions of the interview, probing is appropriate when an answer is unclear, incomplete, inconsistent or no response is given. The best and most frequently employed probe is silence. In a silent probe, the interviewer pauses or hesitates and looks to the participant for an answer. What appears to be dead time to the interviewer may represent the participant's review of a lifetime of events. Other types of probing include repetition of the original question, channeling ("tell me more about ..."), clarification ("when did your doctor tell you that?"), elaboration/ continuation ("what happened next?"), encouragement ("I see, um, huh, hmm") and completion ("anything else?"; "can you tell me anything more about that?").

The most effective, spoken probes are neutral, such as:

"How do you mean that?", instead of "Why?"

"I would like your opinion."

"Can you tell me more about this?"

"Can you give me an example?" or "Can you explain that in a little more detail?"

"How are you using that term?"

"If you had to choose, which would you say?"

"What else can you tell me about that?" instead of "Anything else?"

The cautions in using probes are similar to those for the other interviewing techniques: do not interrupt; do not give the impression you are not listening; do not paraphrase the respondent's words and do not suggest an answer.

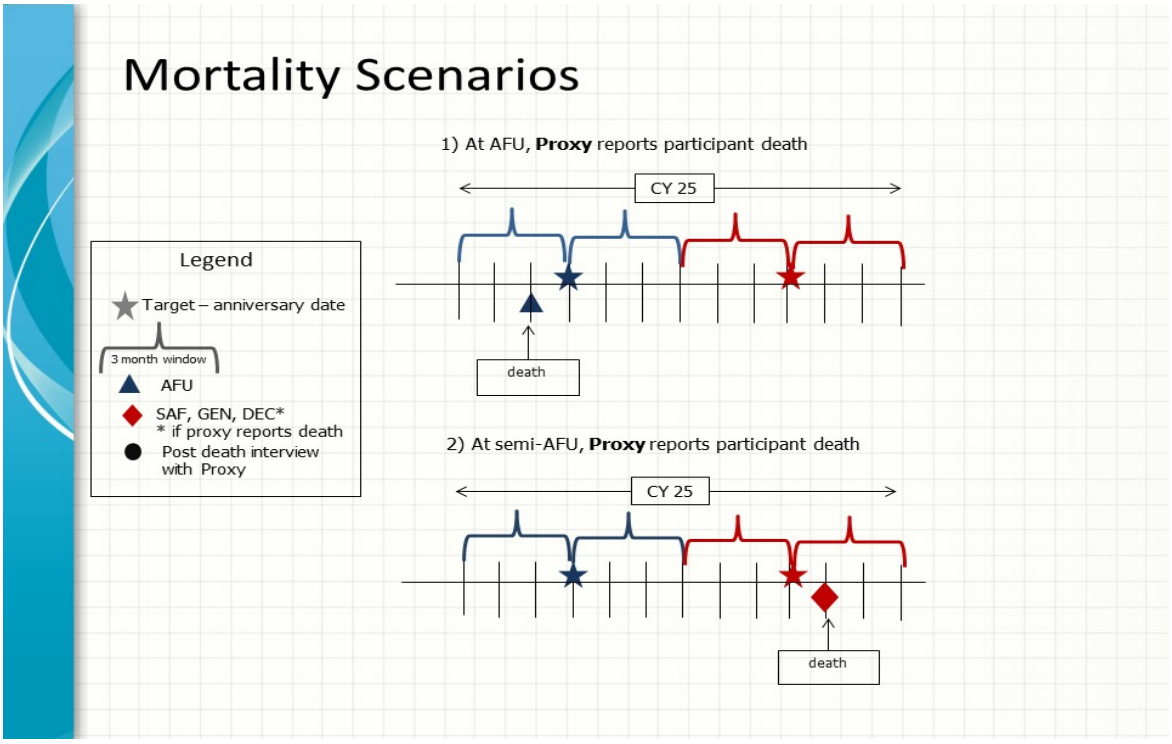
The most frequent obstacles to the administration of a standardized interview are: (1) a perceived conflict by the interviewer between the need to standardize the question or probing approach with the desire to obtain the truth; (2) the interviewer's goals of rapport with the participant being in conflict with standardization; (3) inadequate training of the interviewer; and (4) inadequate training of the participant.

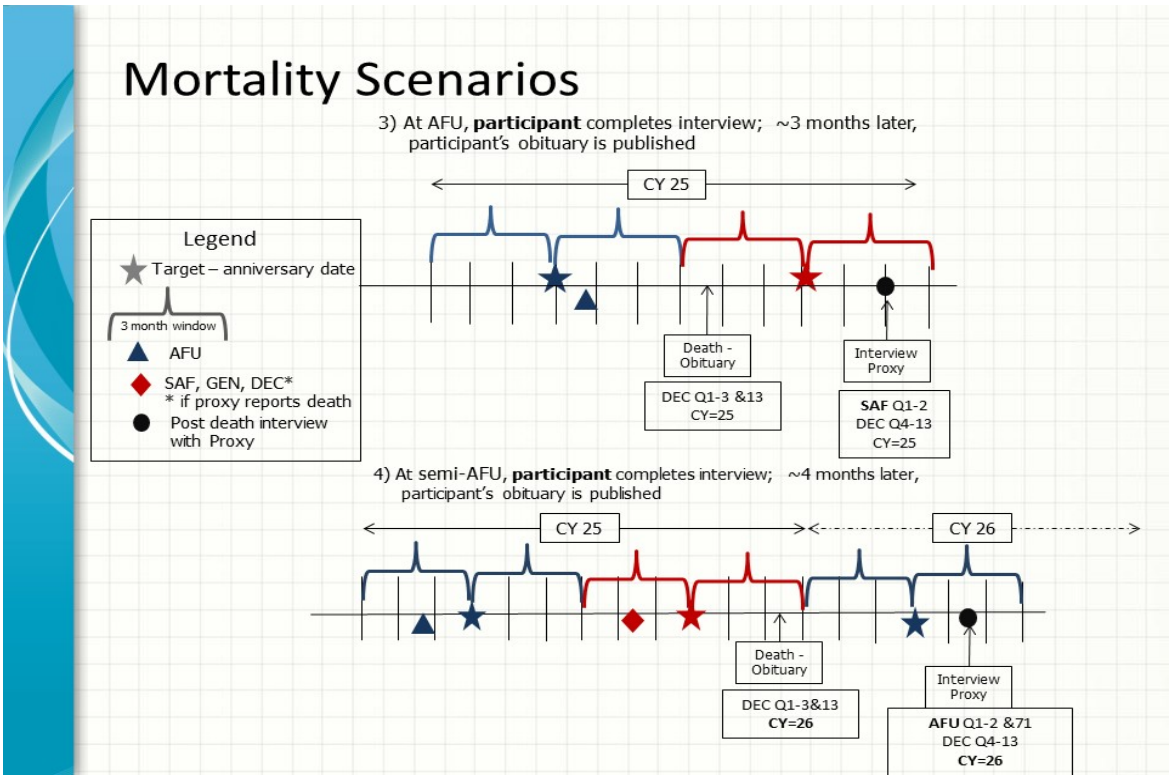
I. Participant Death and Interview Schedule

When the death of a participant is found identified outside of a scheduled interview (e.g., through an obituary or if the death is reported to ARIC by a next of kin), a staff member at the site opens a DEC form under this participant's ID and enters as much information as is available from the obituary or other source about the date and place of death. At least three months are then allowed to elapse, to give next of kin time to grieve, before scheduling an interview with the proxy respondent. At that time, administer the remainder of the DEC and the ADS (see Manual 20 Dementia Surveillance for instructions on the ADS). This action applies to all deaths identified outside of an interview, regardless of the scheduling window during which the death occurred, was identified, or the follow-up interview is made. A DEC form pending resolution may trigger automatic queries from the ARIC CC; these should be considered reminders to assist in managing such pending interviews.

When the follow-up call is made to the proxy respondent, determine the type of scheduling window (AFU or sAFU) during which the interview occurs because the death needs to be documented with either the AFU or SAF form. See Figure 2 for potential mortality scenarios for what forms to complete.

Figure 2. Mortality Scenarios





J. Linkage of Follow-up and Surveillance Activities

The Surveillance staff is to be notified of every cohort hospitalization (and death), and an investigation is initiated by ARIC Surveillance. No information pertaining to these events needs to be returned by Surveillance staff to cohort follow-up personnel.

K. Quality Assurance

Quality assurance is defined as any method or procedure for collecting, processing or analyzing data that is aimed at maintaining or enhancing their reliability or validity.

The purpose of quality assurance is to assure that data is collected in accordance with approved procedures, to maintain high-quality data collection. The ARIC data collection procedures are clearly defined and described in detail in the follow-up documentation. The quality of data collected during interviews is maintained through a series of standardized quality assurance procedures. All interviewer-administered interviews are based on the reading of questionnaires, supported by a Manual of Operations and question by question (QxQ) instructions.

Quality Control Committee (QCC) is designated by the ARIC Steering Committee to coordinate and direct the quality control activities. The QCC prepares recommendations to the Steering Committee in matters of quality assurance, and contacts field centers, reading centers, or laboratories as needed, to advise them of a problem and to discuss the mechanism for correction. The QCC has representation from the CC, field centers, reading centers, laboratories, and NHLBI.

The ARIC Coordinating Center (CC) monitors the study to ensure that the research staff performs those functions to standard. Certification of study personnel is an essential aspect of effective quality assurance as well as quality control in clinical research. In order to maintain proper collection of data despite potential for personnel changes over the study period, the ARIC CC is responsible for establishing and providing the requisite minimum criteria and training and ensuring continued adherence to standards.

Training and certification of interviewers is required to insure proper interviewing technique and data entry accuracy. All interviewers are required to complete structured training sessions provided by the ARIC CC and Field Center Supervisors. Training involves theory and practice in standardized survey interviewing techniques, covering the full range of critical interviewing skills and knowledge, including general interviewing techniques, probing, refusal conversions, quality issues in scientific research, ethics and confidentiality issues. Certification indicates that an acceptable performance standard has been mastered or an adequate knowledge of material has been achieved.

Interviewers are trained and certified in interviewing techniques, the subject matter, terminology, and flow of each data collection form.

Training of interviewers is key to data quality. The purpose of ongoing training is to:

- ensure a uniform application of the study instruments (forms)
- explain the rationale of the study and study protocol
- provide an understanding of the intent of each question/question set

- motivate interviewers
- provide practical suggestions on how to deal with respondents
- improve the overall quality of the data

1. *Interview Schedules*

Conducting interviews at scheduled intervals is critical to ensure that reported data is sufficient and accurate. Additionally, following the guidelines for the timing of interviews can reduce nonresponse and improve retention of participants.

Early contact as soon as the contact window opens will increase the likelihood of achieving a successful contact. Information provided by the DMS collected during previous calls can optimize the timing and length of subsequent calls.

Section II. D. provides the guidelines for scheduling follow-up contacts.

2. *Data Completeness and Data Consistency*

Data completeness means that all information provided by the informant was captured during the interview. Data consistency is achieved when interviewers collect data in the same way, as defined in the Manual of Procedures. Data completeness and data consistency are critical steps in assuring the data quality of the ARIC study's complex instruments. Central and local training, site supervision, and the recertification process help identify and minimize data collection deficiencies to ensure that data collection is comparable among centers. Training provides information to data collectors in a structured manner. Interviewer Supervisors provide immediate feedback on errors. Recertification is the means by which interviewer knowledge about the protocol and competence in data collection can be assessed on a continuing basis, particularly when changes in procedures or definitions are implemented.

To insure that data collection is complete and consistent, it is important to provide regular training with clear instructions on how to use data collection instruments, and how to conduct interviews.

3. *Training and Certification*

Interviewers are trained and certified in general interviewing techniques and the administration of the follow-up interview forms. Current knowledge of procedures and competence in data collection is essential, since follow-up instruments are complex and changing. Supervisors regularly monitor staff interviewing skills. Interviewers who experience difficulty in maintaining their skills are retrained.

Suggestions for interviewer training:

- Review all materials (study instruments, QxQs, Manual) to check understanding of specific question/question sets.
- Review various aspects of data collection, focusing on those aspects that are proving complex and difficult or which are not being adhered to sufficiently by interviewers.
- Conduct mock interviews, using role playing and practice interviews with feedback discussion.

Initial interviewer certification is provided by the ARIC CC. Certification materials are made accessible for review to the Field Centers through the secure website or sent directly to the local supervisor. Certification training will also be provided by the ARIC CC when significant modifications of follow-up questionnaires occur.

Annual recertification among Field Centers is required, with the recommendation of periodic refresher courses and retraining if quality assurance analyses indicate poor performance or inconsistent results.

The ARIC CC has oversight organizing the annual recertification between field centers, known as the Round Robin. This is done locally once a year by review of interviews with actual participants.

Each locally certified interviewer completes three audio-recorded interviews which are uploaded to the ARIC website, entering the data in the DMS, for each type (annual, semi-annual) of interview they conduct for evaluation. The reviewing Field Center Supervisor reviews their designated interviewing Field Center's audio recordings. Supervisors must be certified, and also conduct a minimum of 5 AFU or SAF calls per month to retain their skills and certification. For this purpose, AFU/SAF calls reviewed or observed for quality control purposes count as calls completed by the supervisor.

Reviewers evaluate and rate each interview by completing the Follow-up Interviewer Recertification form (FIR).

Successful completion of recertification consists of demonstrated ability in the following five areas:

(1) Knowledge of the substantive matter in the interview;

(2) Use of an even pace and conversational tone;

(3) Demonstration of a professional and nonjudgmental demeanor;

(4) Use of appropriate probing techniques;

(5) Ability to accurately record the participant's response.

After all reviews have been completed, the ARIC CC prepares a final report by Field Center of scores and recommendations for each interviewer for discussion with the respective Field Center Supervisor and PI, and the ARIC QC Committee.

According to round Robin Results, Field Center Supervisors determine whether interviewers require additional training. Local interviewer retraining is initiated when recertification results show a lack of knowledge of the protocol, lack of adherence to the QxQ specifications, poor interviewing technique, or shortcomings identified in the review process, regardless of the interviewer's overall score. If the retraining is extensive, a new audio recording with three interviews is prepared and submitted for review by the original Round Robin partner.

L. Data Security and Confidentiality

Federal, State and Institutional information security regulations apply to ARIC personnel and to the work done by ARIC. All ARIC personnel are required to be current in their training in ethical conduct of research and in information security training. Information security provisions apply to all data collected in ARIC.

Access to systems and data should be based on the principles of least privilege and separation of duties. No individual should be assigned access privileges that exceed job requirements, and no individual should be in a role that includes access rights that would allow circumvention of controls or the repudiation of actions within the system. In all cases, access should be limited to authorized individuals.

M. The ARIC Data Management System (DMS)

1. Description

The ARIC Data Management System [DMS], also known as CDART is a set of programs provided for collecting data for Annual/Semi-Annual Follow-Up.

The DMS provides the following major functions:

- Data Entry: Allows data to be keyed, edited, and updated. All data entry is done directly into forms in the CDART web based DMS, but Island Mode is available for collecting data off-site and/or off-line.

- Reports: Several reports accessible in CDART provide identifying information about cohort members to help staff make contact with participants.

The ARIC DMS will run on any computer with a high speed Internet connection. Mozilla Firefox and Google Chrome are the preferred browsers.

2. Overview of Data Collection using the DMS

In the course of performing a study, data for a number of participants must be collected at various times for later analysis. These data items are organized into groups of logically related information

called forms or form types. Each form is then assigned a brief mnemonic code for easy reference, i.e. "AFU" for Annual Follow-up Form, “DEC” for Death Information Form, etc.
It is sometimes necessary to change the content of a form during the course of a study. To allow for such changes, a version number is assigned to each form. However, for the General Interview Form, the form code is changed for every new version.

Since follow-up interview forms are collected repeatedly, extra information is included to uniquely identify each recorded instance, or record, of a form. For AFU, SAF, DEC, and the General Interview form, this is contact year.

We refer to all data items on a form as questions and assign a question number to each item. Typical question numbers may include both letters and numbers, e.g. 1, 2, 3a, 3b, etc.

Data items are usually entered directly into the CDART DMS, as this practice results in better data quality than transcribing data from paper forms.

III. APPENDIX

A. AFU CONTACT LETTER

<FC return address>

< Date >

< Address >

Dear < _____ >

I write to remind you that the anniversary date of you first ARIC examination visit is approaching, which is when we have our brief telephone interview each year. I will call you next week to update our information about you, as we do every year. If you prefer to schedule a time at your convenience, please call me at ( ) xxx-xxxx during office hours or send me an email at < _____>.

This year we have added a few additional questions about your health, similar to the ones we asked you before but have not updated for several years. As a result, the interview may last an additional 10 minutes. Also different this year, we would like to learn what medications prescribed for you by a doctor you are taking at this time. To make this easier and to save you time, as part of our telephone interview we will ask you to read the names of the medications you are taking. I want to share this with you prior to the call so that you can make any preparations needed to have your medications on hand.

As always, thank you for being part of the ARIC study. I look forward to talking to you.

(ARIC Interviewer / AFU Supervisor)

Telephone

USPS address

email address

B. Consent to Release Protected Health Information

Consent to Release Protected Health Information

I hereby give my consent for:

_____

doctor(s) and/or health care provider(s)

to provide information from my medical records, including treatments and/or hospitalization between:

_____ and _____

to the *Atherosclerosis Risk in Communities (ARIC) Study* at the University of _____

Purpose, Restrictions, and Re-disclosure:

The health information that is released will be used only for research purposes by the ARIC study at its Field Center at the University of _____ and the ARIC Coordinating Center at the University of North Carolina at Chapel Hill, and will be held in strict confidence. **All information released WILL NOT be re-disclosed.** I place no limitations on information pertaining to diagnosis and history of illness to be used for research by ARIC.

Revocation Statement and Expiration:

I understand that my participation in ARIC is not conditioned upon signing this authorization and that I may revoke the authorization at any time by requesting such in writing to the ARIC Study Field Center at ___ < **address, phone number** > ____, except to the extent that action has already been taken in accord with this consent. This consent is effective upon signing and shall remain valid for the duration of the ARIC study. A photocopy of this document is as valid as the original.

Name:_____**Date:**_____

(PLEASE PRINT)

Signature_____

If legal representative or proxy, sign below and state relationship and authority to do so:

Signature of legal representative/proxy:_____

Relationship/Authority_____

C. Overview of Interview Skills and Techniques

I. Interview bias -- includes anything that creates a systematic difference between responses obtained by different interviewers.

A. Respondent's perception of the interviewer and his/her reaction to that perception.
B. Interviewer's perception of the respondent and his/her reaction to that perception.

II. Characteristics of a good interview:

A. There is an appropriate atmosphere; friendly but business-like.
B. The respondent is at ease. Interviewer should be able to put respondent at ease and ensure their confidentiality.
C. Interviewer obtains the answer to the question asked through proper use of probes and does not interpret questions or try to argue.
D. Interviewer gives only neutral responses to the respondent's answers and clarifies confusing responses but does not challenge an answer.

III. Specific skills required for interviewers include the following:

A. Be able to ask questions at an even pace and in conversational tones.

B. Know the question and response categories well enough to keep the interview flowing smoothly.

C. Know when there are probes that can be used, and know how to use them. Understand when it is inappropriate to probe.

D. Be able to think as an interviewer, putting aside other roles (ECG tech, mother, father, etc.) for the period of the interview. FOCUS on the interview.

E. Be able to maintain a positive attitude about the interview so that the respondent feels that the interview is important.

F. Be able to keep some level of control over the interview process, i.e., by keeping the interview: focused on the specific question and not arguing with the respondent.

G. Ensure that data is coming from the respondent. Listen carefully and avoid being engaged in the answer. Often respondents will use a tack such as, "What do you think?" or "Le~ me tell you about that so that you can help me with the answer." These attempts encourage the interviewer to be "helpful" and can result in bias by leading the respondent to an answer. Remember that you are the interviewer administering the interview, not the respondent being interviewed. We need the information on the respondent, not on you.

H. Interviewers should dress professionally, be neat, pleasant looking. Additionally, they should be not too timid, but not too aggressive.

I. Eye contact with interviewers is very important but by the same token, it is not a good idea "to stare them down" or to act as though you do not believe their answers.

D. Proxy Identification Letter and ARIC Proxy Designation Form

The ARIC Study

Follow-Up by Proxy

A very important goal of the Atherosclerosis Risk in Communities (ARIC) Study is to keep track of any major changes in your health. This information is important for answering scientific questions about heart disease and other health conditions. You are the best source of information regarding your health, but there may be times when you are not able to provide these details yourself. We are asking you to provide us with the name of a person that can answer questions about your health if you cannot. This person will be considered your "proxy" for the ARIC Study. The person you designate would only be contacted once per year, should you be unable to respond. Only your ARIC center can contact your proxy.

What is a proxy?

A proxy is someone who can "stand in" for you and tell us about your health when you cannot because of illness.

Why is a proxy needed?

For almost 20 years you have been providing information about your health to ARIC. This important information should not be lost, even when you are unable to provide it yourself.

What does a proxy do?

Should it be necessary we would ask your proxy to answer questions about your health, just like the questions you have been asked each year by the ARIC staff.

Whom should I name as my proxy?

You should select someone who knows you well enough to provide health information about you. For example, your proxy can be your power of attorney, your legal health care proxy, or your legal next-of-kin (including your spouse, son, daughter, brother, sister, etc).

Am I allowed to change my proxy?

Yes, you may change your proxy at any time by either calling ARIC or by indicating your wishes at your annual ARIC phone call.

Will you give my earlier information to my proxy?

No, all of your information is strictly confidential and will not be provided to your proxy.

What would you like me to do now?

Using the attached form please indicate whom you have chosen to be your proxy. Please indicate his/her name, contact information, relationship to you, sign the form and mail it to the ARIC field center in the enclosed envelope.

We have sent a copy of this form for your own records and one to give to your proxy. This material should be kept by him/her so he/she understands your wishes as a participant in the ARIC Study.

If you have any questions call Mr/Ms. ……. ARIC Study Manager at (xxx) xxx-xxxx

Thank you for your continued dedication to ARIC Study!

The ARIC Study

Participant Name: _____ ARIC ID: _____

First Last MI

I have named as my proxy: _____

(Name of person you choose as ARIC Proxy)

Relationship:_____

Proxy Address:_____

_____

_____

Proxy Phone Number:_____

He/she has the authority to provide medical information, and/or to sign a Medical Release Form to obtain hospital records or physician records for the ARIC Study.

_____ _____
Participant's Signature Date

_____ _____
Witness Date

Complete only if Participant is physically unable to sign: I have signed the Participant's name above at his/her direction in the presence of the Participant and witness.

_____ _____
(Name) (Street)

_____
(City/Town) (State)

Optional: If my ARIC Proxy is unwilling or unable to serve, then I appoint as my alternate ARIC Proxy:

_____
(name of person you choose as your alternate proxy)

of_____
(street) (city/town) (state) (phone)