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APPENDIX 1: SAMPLING, ELIGIBILITY, ENUMERATION, INTERVIEW, & EXAM
Appendix 1.1 Prototype Participant Letter: Initial Contact

Participant letter: Initial Contact

Date:

Address:

Dear _______________:

An important medical project directed by Jackson State University, Tougaloo College and the University of Mississippi Medical Center is being conducted in Hinds, Rankin and Madison counties. It is called the Jackson Heart Study. It is sponsored by the National Institutes of Health and the Office of Research for Minority Health. The object of the project is to understand factors related to heart disease, heart attack, and stroke in African-Americans. Each year approximately 2,150 residents ages 35-84 years will be invited to take part.

You are being invited to participate (as a valued ARIC participant/as a person selected at random (like the flip of a coin) from a list of persons aged 35-84 living in Hinds, Madison, or Rankin County, as a member of the family of NAME).

Eligible people will be interviewed in their homes at their convenience (each interview will take approximately 30 – 40 minutes) and will be invited to a free medical screening clinic where blood pressure, cholesterol, lung function, an electrocardiogram, and body size will be measured and interviews on many factors related to health will be conducted. A check for the presence of atherosclerosis in the arteries of the neck and leg will be performed using ultrasound, a painless test which measures reflected sound waves. Three to four years after entry onto the study, participants may have another physical evaluation like the first.

The information collected will be held strictly confidential and used only for statistical, research purposes. The project will provide important information on your health status and will aid physicians in understanding the causes of heart attack and stroke. Your household is a valuable part of this effort.

[ A trained field interviewer from our staff will call on you in your home soon.] We thank you for your assistance in this project.

Sincerely,

[Field Center Director]

Enc: JHS Brochure

JHS Newsletter
Appendix 1.2  JHS Information Brochure
Appendix 1.3  JHS Newsletter
Appendix 1.4 Prototype Employer Letter: Request for Release from Work

Dear Employer:

Your employee, [NAME], has been selected to participate in an important medical research project called the Jackson Heart Study (JHS). This project is sponsored by the National Heart, Lung, and Blood Institute in the Jackson Metropolitan area. It is being conducted by Jackson State University, Tougaloo College and the University of Mississippi Medical Center. The purpose of the study is to better understand characteristics which may predispose African-Americans to heart or blood vessel diseases.

The JHS requires a four and one-half hour examination now and in three to four years to collect the medical information. We hope you will allow your employee time off to complete this examination. Her/his participation is important to the study. If you have any further questions you may call me at [telephone number].

Thank you.

Sincerely,

[Principal Investigator]
### Appendix 1.5  Jackson Area Medical Facilities Coding List

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<th>Name</th>
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<th>Code</th>
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Appendix 1.6  Participant JHS Baseline Examination Visit Information Packet
Appendix 1.7  JHS Consent Brochure

The Jackson Heart Study Consent Brochure

Information I Need

Before Making

An Informed Decision to Participate?
Purpose of this Brochure  The purpose of this brochure is to provide information about the Jackson Heart Study, why and how you were selected, what you can expect if you decide to participate, and details that will help you make an informed decision to participate.

What is the Jackson Heart Study?  The Jackson Heart Study (JHS) is a medical research study conducted by the University of Mississippi Medical Center, Jackson State University, and Tougaloo College and sponsored by the National Heart Lung and Blood Institute (NHLBI) and the Office of Research on Minority Health (ORMH). It will try to find out why heart disease is more common and more deadly among African-Americans, including why high blood pressure and heart disease tends to run in some families. An increased understanding of lifestyle and inherited characteristics related to heart disease will improve the ability to prevent high blood pressure and heart disease, including strokes, heart attacks, diabetes (sugar) and kidney disease among African-Americans and others. Your participation can help find answers which may assist in preventing and treating heart disease, thus leaving a legacy of health for years and generations to come.

Who is in Charge?  Dr. Herman A. Taylor, an African-American cardiologist, native of Alabama, is the overall Principal Investigator and Director of the study.

How Was I Selected to Participate?  You were selected because you have identified yourself as an African-American and are between the ages of 35 and 84 and live in the tri-county area surrounding Jackson. We will be asking a total of 6,500 people to participate between September 2000 and August 2003.

There are 3 ways of being selected: You participated in the Atherosclerosis Risk in Communities (ARIC) Study, someone in your household was randomly (like a flip of a coin) selected from the Mississippi Drivers License and Identification List, or you were identified as a relative by another family member who is already taking part in the JHS.

What Will I Be Asked To Do?  Participation in the JHS involves different activities. You will be asked to take part in a variety of interviews, examinations, and laboratory tests, including storage of samples for later genetic tests, and review of medical records.

Initial Contact
A Home Induction Interview
A Family Tree Chart
Self-Administered Questionnaires
A Clinic Visit
24-hour Studies
Annual Follow-up
Medical Records Review
Initial Contact:

Once your name is selected, one of our staff will mail a letter to your home informing you that your name has been selected for the JHS. Within two weeks, this person will come to your home. A few questions will be asked to verify your identity and your eligibility for the study.

Home Induction Interview:

While at your home, the same staff will administer a 30 minute questionnaire. If it is not convenient for you, an appointment to call back will be set up at your convenience. This interview aims at obtaining information about:

- your health and health care; your lifestyle including diet and exercise, drinking and smoking;
- the medical history of your family;
- your (and your family=s) occupation, education, income;
- how you deal with life situations such as stress and discrimination; and

To assure that all the questions are asked in the same way of everyone, some interviews may be tape-recorded so that their administration can be compared.

Family Tree Chart:

Self-Administered Questionnaires:

Clinic Visit:

The clinic is located at the Jackson Medical Mall.

The examinations will include a number of routine tests commonly performed in your doctor=s office plus some additional exams to get a better picture of the function of your heart, blood vessels (arteries) and lungs. All of these procedures are painless. Specifically, you will undergo examinations to:

- measure your height, weight, waist, neck and hip circumference;
- measure your blood pressure at rest (in the clinic) and for 24 hours following the end of your clinic visit. You will be asked to wear a blood pressure monitor on leaving the clinic which will be picked up the next day by study personnel;
- measure your electrocardiogram (ECG) which provides a tracing of your heart beat. This involves attaching electrodes (band-aid like stick-ons) to your chest to measure the electrical activity of your heart;
- take Apictures, using sound waves, of your heart (echocardiogram) and the arteries in your neck (carotid ultrasound). This involves moving a small electronic device across the surface of your chest and neck;
• test your lungs by having you blow air into a machine (spirometer).

The laboratory tests will include blood and urine tests to check for such things as cholesterol, potassium, sodium, hormones, kidney function, sugar levels, and future genetic (inheritance or DNA) tests. Specifically, 12 or more hours after your last meal, you will be asked to:

• provide approximately 2 1/2 to 3 ounces of blood from a vein in your arm. This is about 5 tablespoons of blood that will be drawn, or approximately 1/10 of the amount drawn during blood donations;
• collect all of your urine in special bottles for 24 hours after your clinic visit. This urine sample will be picked up the next day by study personnel.

The genetic (inheritance or DNA) tests are an important part of the JHS. This involves testing of genetic material (DNA) in blood cells to find genes that may cause or protect people from high blood pressure, heart disease, stroke or their risk factors. To do this, a small sample of your blood will be used to prepare DNA and to start a living tissue sample (cell line) which will provide an unlimited supply of DNA in the future without the need for any more blood from you. By having this cell line, the JHS would be able to study the importance of genes that haven’t been thought of yet. Blood cells will not be sold for commercial purposes or used for cloning.

The review of records includes getting a copy of your birth certificate in order to record your weight at birth, your social security number, and copies of your hospital and physician’s medical records. Specifically, if you are hospitalized for any reason, using your social security number, study personnel can check your medical records to obtain medical information that may apply to this study. If you have (or have had) a heart attack or stroke before the end of the study time, or if you were to die, study personnel could ask your relatives and physicians for details about your illness.

How do I know that these tests are safe?

All of the examination procedures at the JHS are considered safe. These tests are routinely included as part of standard medical examinations and carry a very low risk of side effects.

What are some of these side effects or risks from taking part in this study?

There may be some slight discomfort during the blood drawing, however a skilled technician will draw your blood. There is practically no risk of infection since sterile disposable needles and syringes are used. Some
people may feel a little faint and there is a slight risk of bruising at the site of the needle insertion. No materials will be injected into your body; only blood will be withdrawn.

The EKG and ultrasound tests are performed in a lying position. You will be asked to remain very still and may be asked to stay propped on your side for some of the examination. This may be slightly uncomfortable, but will last a short time. There may be some discomfort from the repeated blood pressure measurements both in the clinic and over the 24-hour measurement time.

Some of the background questions are personal and may be considered sensitive. You may be asked about stressful life situations as well as relationships of members of your family. You may experience some embarrassment when answering them. Some of the questions may bring back bad memories which may cause you some mental distress. An experienced social worker will be available to you if you would like to talk about any of these memories.

Another possibility is that you may learn of some health condition that you did not know that you had. This is a concern to some people who would rather not know, or who do not have insurance or a regular source of health care. Since this study does not include any medical treatment, the researchers cannot provide medical care for any condition which might be found. However, the study will help you to find appropriate, affordable medical care for any conditions identified. If you have any of these concerns, a JHS social worker will be available to talk with you.

There may be risks associated with you or your physician having the results of any future DNA tests as such information may then become part of your medical record. Since insurance companies routinely have access to such information, this could decrease your ability to get health or other insurance. Also, family relationships you did not know about could be uncovered. Some of these risks may be avoided by choosing not to learn your genetic research information when it becomes available. All DNA results will be kept confidential and will not be sent to anyone, including you, your family members or any third party unless you expressly ask for them. If you want to know your genetic information, you must complete a formal request process. This is because the significance of genetics testing is not fully known at this point in time and may have no clear meaning for you as an individual.

What will I get out of taking part in this study?
One benefit to you is the free evaluation of your health including specialized heart and lung testing. You will receive a summary letter of the normal or abnormal results from this examination, including your blood pressure, blood cholesterol and other heart information. In addition, if you give permission, a copy of these results will also be sent to your regular health care provider. In the event that any abnormalities or risk factors are found, your health care provider will be able to discuss these with you. Should you not have regular health care, or be unable to afford such care, the JHS will assist you in locating affordable health care. Study investigators or their colleagues may re-contact you for further information about your health in the future or to notify you of test results that are important for your health. However, since this is a research study, and the examination you receive is not a substitute for one you would receive from your health care provider, we cannot make a diagnosis, provide treatment, or give medical advise related to any condition.

Regular educational programs will be held at the JHS clinic and throughout the community for study participants to offer further health information about how to prevent your risk of heart disease and to stay heart healthy. All study participants will also receive a regular newsletter updating them on the overall findings of the JHS.

Although you may not receive any direct benefit from this research other than up-to-date personal health information, you will have the satisfaction of knowing that you have contributed to developing new knowledge about the causes and risk factors for high blood pressure and heart disease in African-Americans. Persons who develop heart, blood vessel and other disorders in the future and their families, as well as future generations of your family, may benefit if we can locate the causes of these illnesses. This study may contribute to the development of new methods of prevention and treatment of these diseases, thus leaving a legacy of health for generations to come.

**Will this cost me anything?**

The only cost to you is your time. There is no cost for any of the interviews, medical examinations or laboratory tests. Parking at the Jackson Medical Mall, the site of the JHS clinic, is free. Transportation and child care, if needed, will be reimbursed or provided.

**Will I receive any payment for taking part?**

Each participant will receive their choice of $25.00 in cash or gifts in appreciation for taking part in the study.
Are there any alternatives to taking part in this study?

The alternative is to decide not to take part in this research study. You can, however, have some of these tests, including some of the genetic tests, through a regular health care provider at the cost of your personal insurance or out of pocket.

How can I be assured that my results will be kept confidential?

All information collected during this research—including interviews, laboratory data, genetic information, or findings of examinations—will be kept confidential and will not be disclosed without your permission to anyone (including members of your family) except the researchers conducting the JHS or as otherwise required by law. However, research records, just like hospital records can be subpoenaed (formally requested) by court order. A Certificate of Confidentiality has been obtained for the Jackson Heart Study that will protect you from compelled disclosure (for example, being forced to release information by court order) of any identifying characteristics known by the JHS. If you give your permission, the results of your tests can be reported to your health care provider. You may also request and authorize, by signature, the release of information to other appropriate agencies or persons.

To assure confidentiality, a code number will be assigned to you and your name will not be used on any information or samples you provide. Only the code numbers will be provided to qualified researchers studying the samples or information. The coded information and samples will be stored securely, in locked files which are separated from files which link your name to the code numbers.

Your information and samples will be kept indefinitely for analysis and follow-up. Samples will be stored without identifying information and with maximum security, as outlined by all federal regulations. The information from any analysis of your DNA will not be released or shared in any way with your relatives, insurance companies or any other third parties unless you specifically request that we do so. With your permission, these DNA samples will be provided without any names or other personally identifying information to researchers conducting the JHS and other qualified researchers (we have an extensive screening process) interested in inheritance of heart, lung and blood diseases and other related diseases or health conditions. Confidentiality will be further protected by requiring that those scientists who receive data must agree to sign and abide by a Confidentiality Agreement which requires that confidentiality will be kept and established JHS standard rules and regulations will be followed.
Your information will be grouped with that of all other persons taking part in the JHS and will be used only for statistical analysis to further medical knowledge without disclosing your personal identity. When results of this study are published, presented at medical or research meetings, or to the Jackson community, only group findings will be presented.

Federal law allows other scientists or groups to request information obtained by this study. You may be asked if you wish to take part in new studies conducted by the JHS or other researchers. With your permission and approval, your study data, including information from interviews, samples of blood, urine or DNA, can be released to others only after removal of all identifying information.

**What about any research-related injuries that might occur while I am in the JHS?**

In the unlikely event that during the examination procedures you should require medical care, or injury occurs as a result of any of the procedures, prompt medical treatment will be provided according to usual and customary standards of medical practice.

Jackson State University, Tougaloo College, nor the University of Mississippi Medical Center have a mechanism to provide compensation for subjects who may incur injuries as a result of participating in biomedical or behavioral research. This means that, while all investigators will do everything possible in providing careful medical care and safeguards in conducting this study, there is no way in which the institution can pay for the unlikely occurrence of injury resulting solely from the study itself. We will, of course, provide the best medical treatment to which you are entitled for the illness, if any, for which you consulted us whether or not you participate in this study or whether or not you decide to withdraw from the study.

In the event that the examination uncovers any medical problems that require medical diagnosis or treatment, you will be so advised and, if you agree, that information will be provided to the clinic or health care provider of your choice. In that case, payment must be provided by you or your third party payer, if any (for example, Medicaid, Medicare, health insurance). As previously discussed, the JHS will help you to find affordable health care if you cannot afford to pay or have no regular health care provider.

**What if I decide I no longer want to take part in this study?**

Your participation in the JHS is completely voluntary and you are free to withdraw your consent and to stop taking
part at any time, without affecting any future relationship for you or your relatives with the JHS or the University of Mississippi Medical Center, Jackson State University, or Tougaloo College. You may decide not to answer any question or complete any examination, and you may request that your records, blood and DNA samples, and test results be removed from study files. You may also request that your DNA samples be destroyed or that all identifiers be removed (including code numbers) from such samples. Your refusal to answer any of the questions will not result in any loss of benefits to which you are otherwise entitled.

What if I have questions about the study?

Any questions about the study, the specific interviews, examinations, laboratory tests, or record reviews, or any questions about the findings of the study can be answered by the Director of the Jackson Heart Study, Dr. Herman Taylor. He can be reached at:

Jackson Heart Study
Jackson Medical Mall
350 W. Woodrow Wilson Drive
Jackson, MS 39213
815-5050

After hours and on weekends you may reach a study investigator by calling xxx-xxxx.

What if I have questions about my rights as a research participant?

This research study has been reviewed by the Institutional Review Boards of The University of Mississippi Medical Center, Jackson State University, and Tougaloo College. Any questions about your rights as a research participant can be addressed to one of the following persons:

Stanley Chapman M.D.  Cynthia Ford PhD  Lewis Jones PhD
Chair, IRB  Chair, IRB  Chair, IRB
University of Mississippi Medical Center  Jackson State University  Tougaloo College
2500 North State Street  1400 J.R. Lynch Street  500 West County Line Road
Jackson, MS 39216-4505  Jackson, MS 39217  Jackson, MS 39174
601-984-5560  601-968-2931  601-977-7737
 Appendix 1.8  Participant Information Sheet (PART)

Participant Information

Thank you for agreeing to participate in the Jackson Heart Study. Your appointment has been scheduled for:

DAY ____________________ DATE __________ TIME ________________ A.M.

Please come to 350 West Woodrow Wilson, Jackson Medical Mall, Jackson Heart Study Clinic. A map and parking directions are attached. Please read the following instructions carefully.

- **FASTING:**
  You should **NOT** eat or drink anything except water and your medications for 12 hours before your appointment time. This includes chewing gum, mints or any other food. A snack will be provided during your visit. **Except for medications that must be taken with food** (such as insulin), remember to take **ALL** your regular medicines with water before coming to the clinic. If you are taking medicine for your blood pressure, be sure to take it as usual.

- **SMOKING AND PHYSICAL ACTIVITY:**
  Please **DO NOT** smoke or do vigorous physical activity for at least one hour before your appointment.

- **CLOTHING:**
  Please be prepared to change into a hospital gown after your arrival and bring or wear comfortable shoes or slippers that are easy to take on and off. Please wear loose fitting underwear and leave necklaces at home.

- **MEDICATIONS:**
  Please be sure to bring **ALL** your medications including prescriptions, over the counter vitamins, or herbs in their original containers. You should put these containers in the Jackson Heart Study medications bag. You may refer to the Medications Information Listing to remind you of all the possible medicines you might be taking. If you are taking insulin, bring both your insulin and syringes to the clinic so you can take it before your snack.

- **GLASSES:**
  If you normally use glasses for reading, please bring them with you to the clinic.

- **PHYSICIAN CONTACT:**
  Please complete the attached card providing the name and address of your health care provider and bring it with you to the clinic.
It is most important that you be on time for your appointment. Here is a schedule of activities for your clinic visit with average times for each activity:

<table>
<thead>
<tr>
<th>Activity</th>
<th>Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Welcome and Consent</td>
<td>15 minutes</td>
</tr>
<tr>
<td>Height, Weight and Blood Pressure Measurement</td>
<td>20 minutes</td>
</tr>
<tr>
<td>Diet and other Interviews</td>
<td>25 minutes</td>
</tr>
<tr>
<td>Ultrasound Echo</td>
<td>70 minutes</td>
</tr>
<tr>
<td>Pulmonary Function Tests</td>
<td>15 minutes</td>
</tr>
<tr>
<td>Blood Drawing</td>
<td>10 minutes</td>
</tr>
<tr>
<td>Electrocardiogram</td>
<td>15 minutes</td>
</tr>
<tr>
<td>Snack</td>
<td>15 minutes</td>
</tr>
<tr>
<td>Medical Review</td>
<td>10 minutes</td>
</tr>
<tr>
<td>Medical History</td>
<td>50 minutes</td>
</tr>
<tr>
<td>Prepare for 24 hour Tests</td>
<td>15 minutes</td>
</tr>
</tbody>
</table>

If you have any questions or a problem with your appointment, please call the clinic at 815-5050 between 7:30 a.m. and 4:30 p.m. Tuesday through Saturday.

We look forward to meeting you.

Jackson Heart Study Staff

The name of your interviewer today is ________________________________.

*You may contact your interviewer at 815-5050 if you have any questions before your appointment.
Appendix 1.9  Medication Instructions Information (MIN)

Medication Instructions Information

PLEASE BRING WITH YOU TO THE CENTER:

- Prescription Drugs from your physician
- Prescription Drugs you have been given by a friend or relative
- Non-prescription Drugs (over the counter that you obtained from a drug store, supermarket, or by mail, such as aspirin, cold remedies, vitamins, herbals or “natural” medicines, or the likes.

THAT YOU HAVE TAKEN FROM ____________________ TO ____________________

In order to be sure you have included everything, think about the past few weeks when you may have seen a health care provider who gave you medications, or you may have talked with a friend or family member who remembered you use a medicine, herb, or root for any problem you might have.

Also, please review this list of reasons why many people take medication.

GROUP A
Lung problems – such as asthma, lung disease, emphysema, shortness of breath, wheezing
Arthritis, joint pain, for example, cortisone-type medicine, anti-inflammatory drugs
Vascular problems, blood thinning, for example, dicumarol, coumadin
Heart problems, angina, for example, digitalis, nitroglycerin
Diabetes – insulin or pills
Cancer
Ulcers, stomach, digestion

GROUP B
Chest pain
High Blood Pressure
Seizures
Flu, pneumonia
Skin problems
Coughs and colds
Headaches
Nausea

GROUP C
WOMEN – oral contraceptives, pills for hot flashes or to regulate periods, relieve menstrual problems

GROUP C (continued)
Hormones
Steroid, cortisone
Shots or pills to lose water from your body
Thyroid
Allergies
Ear, eye, nose drops or ointments

GROUP D
Pain, for example, codeine, Darvon, Percodan, Demerol, Tylenol #3/#4
Infection, for example, penicillin, sulfas, other antibiotics
Muscle relaxants
To reduce fever

GROUP E
Weight reducing aids (appetite suppressants)
To combat anxiety, depression
To improve regularity, relieve constipation
Relaxation
Sleep

GROUP F
Iron or anemia medicine (don’t forget Geritol)
Vitamins or mineral supplements
Herbs or cold remedies.

ALL INFORMATION COLLECTED FOR THIS STUDY IS HELD IN CONFIDENCE AND USED ONLY FOR STATISTICAL RESEARCH PURPOSES.
Participant Information

Ambulatory Blood Pressure Monitor (ABPM)

Thank you for agreeing to participate in ambulatory blood pressure monitoring for the Jackson Heart Study. Your blood pressure monitor is to be worn continuously starting today at ____________ until ________________ on _________________ (date).

- Once your blood pressure monitor is placed on your arm at the JHS Clinic, please do not remove it unless instructed to do so by the Study Coordinator until the time and date noted below or in the case of an emergency.

- The “START/STOP” button is used to start or stop a reading and should be used only in an emergency or upon instructions of the Study Coordinator.

- Follow a normal routine of daily activities with the monitor in place. Take all of your regular medications as prescribed by your health care provider.

- The blood pressure cuff will take readings automatically every 20 minutes throughout the 24-hour monitoring period.

- During the day, a beeping sound will be heard PRIOR TO THE ABPM TAKING A READING. Before each reading you will hear two tones. A single beep will be heard if the reading is successful. If the reading was not successful, you will hear five short tones. These beep sounds will be turned off automatically at night.

- The most likely reason for an unsuccessful reading is too much motion. When a reading is being taken, avoid moving. LIE, STAND OR SIT STILL AND RELAX. While driving, relax your arm above your lap assuring that the arm is not in contact with the car or your body.

- Another common reason for unsuccessful reading is the cuff is too loose or has slipped down too far on your arm. Periodically check the
placement of your blood pressure cuff. Make sure that the “Artery Arrow” remains over the “T” marked on your arm during cuff placement. If the cuff slips or becomes too loose, adjust it as you were taught at the clinic.

- If an unsuccessful reading occurs (5 BEEP TONES), another reading will be ATTEMPTED in two to three minutes. REMEMBER a successful reading will be verified by a single beep.

- If unsuccessful readings continue to occur (AUTOMATIC READING FOLLOWED BY THE ATTEMPTED REPEAT), call the JHS clinic.

- DO NOT take a shower or get the monitor wet.

- AVOID use around microwaves or other electronic security equipment, for example at the video store.

- When sleeping, place the monitor between a pillow and its pillowcase and place it in the bed with you. DO NOT place the monitor on the floor or on a nightstand.

If you have questions or need assistance, contact the Jackson Heart Study Examination Center at 815-5050.

Your appointment for removal of the blood pressure cuff is scheduled for:

DATE________________________ TIME___________________

PLEASE RECORD THE TIME YOU GO TO BED AND THE TIME YOU GET UP:

GO TO BED_________ am/pm  GET UP___________ am/pm
Appendix 1.11  Participant Instructions: Removal of Ambulatory Blood Pressure Monitor (ABPMR2)

Participant Information
Repositioning and Removing Ambulatory Blood Pressure Monitor (ABPM)

Please do not remove the blood pressure monitor unless absolutely necessary. If it becomes necessary to remove the ABPM unit, the following steps should be taken:

- On the ABPM unit, please press the BLUE start/stop button. This will start the unit to take a reading.
  Please record the time from the ABPM unit:
  _____________hr. _____________min.

- Once the reading is complete, remove the ABPM unit from the blue pouch. On the bottom of the ABPM unit, there is an “ON/OFF” switch. Please move the switch to the OFF position. There should be no display of the time on the ABPM unit.

- Remove the cuff by pulling and separating the Velcro® attachment. The cuff should still be “looped” through the plastic ring on the cuff.

When you are ready to reapply the blood pressure cuff, the following steps should be taken:

- Put the cuff on your arm with the plastic tubing coming from the top of the cuff up to the shoulder.

- Make sure the “Artery Arrow” is in line with the “T” which was drawn on your arm during cuff placement in the clinic.

- Once the arrow and T are in line, tighten the cuff by pulling the loose piece of cuff material through the plastic ring on the cuff.

- Make sure that the connector piece at the end of the cuff tubing is firmly attached to the ABPM unit.
• On the bottom of the ABPM unit, please move the switch from the off position to the ON position. Please record the time from the APBM unit:

______________hr. ____________ min.

• The time should now be displayed on the ABPM unit.

Please record the time, which is displayed on the ABPM unit, and then press the BLUE start/stop button to have the ABPM unit take a reading.

Please contact your Jackson Heart Study coordinator (601) 815-5050 with any questions or for help while you are wearing the ABPM unit.
Appendix 1.12 Checklist for Applying ABPM
Appendix 1.13 Medical Data Review Printout For JHS Baseline Visit

17. Name (CON 1,2,3,4): ……………

18. ID Number: ………………………………

19. Date of Birth (ELG5): …………………
   m   m   d   d   y   y   y   y

20. Date of Visit (FTR1): …………………
   m   m   d   d   y   y   y   y

21. Age in years (ELG5, FTR1): …………. ……………

22. Health Care Provider (CON34a, b.):

23. Height (ANT1): …………………………
   '   "

24. Weight (ANT2): …………………………
   ………………………………………………………

25. Average sitting BP (SBI19/SBI20): …………
   /   /

26. Participant currently taking antihypertensives (MSR30a)? ………… ….. Yes Y

27. No N

28. Health Care Provider ever said you had High Blood Pressure (PFH2a)? ………….. Yes Y
<table>
<thead>
<tr>
<th></th>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>12</td>
<td>Health Care Provider ever said you had Diabetes (PFH6a)?</td>
<td>Yes Y</td>
</tr>
<tr>
<td></td>
<td></td>
<td>No N</td>
</tr>
<tr>
<td>13</td>
<td>Health Care Provider ever said you had High Cholesterol (PFH3a)?</td>
<td>Yes Y</td>
</tr>
<tr>
<td></td>
<td></td>
<td>No N</td>
</tr>
<tr>
<td>14</td>
<td>Health Care Provider ever said you had a stroke (PFH5a)?</td>
<td>Yes Y</td>
</tr>
<tr>
<td></td>
<td></td>
<td>No N</td>
</tr>
<tr>
<td>15</td>
<td>Health Care Provider ever said you had Cancer (PFH8a)?</td>
<td>Yes Y</td>
</tr>
<tr>
<td></td>
<td></td>
<td>No N</td>
</tr>
<tr>
<td>16</td>
<td>Health Care Provider ever told you had kidney problems (PFH8a)?</td>
<td>Yes Y</td>
</tr>
<tr>
<td></td>
<td></td>
<td>No N</td>
</tr>
<tr>
<td>17</td>
<td>[FOR FEMALES ONLY] Uterine bleeding (RHXB4)?</td>
<td>Yes Y</td>
</tr>
<tr>
<td></td>
<td></td>
<td>No N</td>
</tr>
</tbody>
</table>

ECG: Read tracing.

19a. Significant findings in preliminary interpretation:

_____________________________________________________________________________
_____________________________________________________________________________

19b. Was a physician notified?                                      Yes Y

19c. If yes, physician’s name:
19d. Date notified: .....................

20a. Other significant findings? ................................................................. Yes Y
      No N

20b. If yes, summarize: ________________________________________________________________
      ________________________________________________________________________________
      ________________________________________________________________________________

M.D. Review - M.D.'s Interpretation of ECG:

21a. Summary of significant findings: ______________________________________________________
      ________________________________________________________________________________
      ________________________________________________________________________________

22. Was a referral made? ................................................................. Yes Y
      No N

[IF YES, SPECIFY ON REPORT AND REFERRAL FORM]

23. Code of person completing
    Medical Data Review: .................................................................

24. Date of Medical Data Review: ............
    ________________________________________________________________________________

25. Code of person completing
    Medical Data Review: .................................................................
26. Date of Review by M.D. : ....................

<table>
<thead>
<tr>
<th>m</th>
<th>m</th>
<th>d</th>
<th>d</th>
<th>y</th>
<th>y</th>
</tr>
</thead>
</table>
APPENDIX 2: PARTICIPANT AND HEALTH CARE PROVIDER RESULTS REPORTING
Appendix 2.1 JHS Baseline Clinic Visit Report
Appendix 2.2  Summary of Baseline Clinic Results

JHS VISIT 1 RESULTS FOR PARTICIPANTS AND THEIR HEALTH CARE PROVIDERS

Participant’s name: pt full name~
Date of visit to the JHS exam center: dov~
Birth Date: dob~  Our reference (JHS ID): jhs #~

These are the results of your JHS Visit 1 Examination

Weight: wt. pounds  Height: htft~ ft.  htin~in  (htcm~ cm)
Blood Pressure:  systolic/diastolic mmHg (Average of 2 measurements)

A. If on antihypertensive medication, and SBP <160 and DBP<85:

“If you are being treated for high blood pressure, your health care provider may have given you a schedule for your next check up. Please follow that schedule.”

B. If NOT on antihypertensive tx, SBP<130 and DBP<85:

“Your blood pressure was normal. Please recheck it in two years.”

C. If NOT on antihypertensive tx, SBP 130-139 and DBP 85-89:

“Your blood pressure was high normal. Please recheck it in one year.”

D. If NOT on antihypertensive tx, SBP 140-159 or DBP 90-99; choose SBP or DBP, whichever falls in the higher category:

“Your blood pressure reading was elevated. At the time of your JHS visit, we indicated that you should have your blood pressure checked within two months by a health care provider.”

E. If SBP 160-179 or DBP 100-109; choose SBP or DBP, whichever falls in the higher category:

“Your blood pressure reading was elevated. At the time of your JHS visit, we indicated that you should have your blood pressure checked within a month by a health care provider.”

F. If SBP 180-209 or DBP 110-119; choose SBP or DBP, whichever falls in the higher category. Health care provider is sent an alert letter (Appendix 7.2.3):

“Your blood pressure reading was clearly and importantly elevated. At the time of your JHS visit we indicated that you should see your health care provider within one week, to determine whether treatment should be started or changed. If you have not done so already, please see your health care provider soon.”

G. If SBP \geq 210 or DBP \geq 120; choose SBP or DBP, whichever falls in the higher category. Health care provider is called:
“Your blood pressure reading was very high. At the time of your JHS visit we indicated that you must see your health care provider at the earliest opportunity to confirm this finding. If you have not done so already, please see your health care provider at once.”

Electrocardiogram

A. Normal ECG, participant has health care provider:

“Your electrocardiogram is normal or has insignificant findings. Your electrocardiogram has been sent to your health care provider with a copy of this report.”

B. Normal ECG, participant does not have a health care provider:

“Your electrocardiogram is normal or has insignificant findings. Your electrocardiogram is enclosed.”

C. Minimally Abnormal ECG, has health care provider:  
Health care provider is sent letter (Appendix 7.4.3). Participant is sent letter (Appendix 7.4.1).

“Your electrocardiogram has an abnormal finding but shows no significant changes since your last JHS visit. Your electrocardiogram has been sent to your health care provider with a copy of this report.”

D. Minimally Abnormal ECG, participant does not have a health care provider.
Participant is sent letter (Appendix 7.4.2).

“Your electrocardiogram has an abnormal finding. Your electrocardiogram is enclosed.

E. Important abnormal changes on ECG, participant has health care provider:  
Health care provider is called or; health care provider is sent alert letter (Appendix 7.2.3); Participant is sent alert letter (Appendix 7.2.1).

“Your electrocardiogram shows some abnormal findings. Please check these results with your health care provider if you have not already done so. Your electrocardiogram has been sent to your health care provider.”

F. Important abnormal changes on ECG, participant does not have a health care provider:  
Participant is sent alert letter (7.2.2).

“Your electrocardiogram shows abnormal findings. Please check these results with a health care provider if you have not already done so. Your electrocardiogram is enclosed.”

Carotid Ultrasound

A. If Routine (no alert values):

“The JHS study performs a limited ultrasound examination of portions of the carotid arteries (blood vessels in the neck). We found no blockage in the artery segments examined. We consider blockage to be present if the opening of an artery is reduced to 2 millimeters or less.”

B. If Alert:
Participant is sent letters (Appendix 7.5.1 or 7.5.2). Health care provider is sent letter (Appendix 7.5.3).

“We have previously sent a report suggesting that you see your health care provider about a finding noted in your ultrasound examination of the arteries in the neck.”

---

**Echocardiogram**

1. If Routine (no alert values):

   “Although a total echocardiographic assessment of your heart wasn’t performed, the parameters assessed – ejection fraction and heart size were normal based on our reading center standards.”

2. If Alert:
   
   Participant is sent letter (Appendix 7.5.1 or 7.5.2). Health care provider is sent letter (Appendix 7.5.3).

   “We have previously sent a report suggesting that you see your health care provider about a finding on your echocardiogram (ultrasound picture of your heart).”

---

**Pulmonary Function Tests**

(See Preliminary Pulmonary Function Report, Appendix 7.1.2).

<table>
<thead>
<tr>
<th>CHEMISTRIES</th>
<th>Reference Range for JHS Labs</th>
<th>Results</th>
</tr>
</thead>
</table>
| Total Cholesterol          | <200 desirable  
|                            | 200-239 mildly elevated  
|                            | >240 markedly elevated    |         |
| LDL                        | <130                         |         |
| HDL                        | >35                          |         |
| Triglycerides              | <220                         |         |
| Creatinine (males)         | 0.7 – 1.4                    |         |
| Creatinine (females)       | 0.5 – 1.2                    |         |
| Fasting glucose            | 74 – 106                     |         |
| Sodium                     | 136 – 146                    |         |
| Chloride                   | 98 – 108                     |         |
| Potassium                  | 3.5 – 5.1                    |         |
| Uric Acid (males)          | 3.5 – 8.5                    |         |
| Uric Acid (females)        | 2.5 – 7.5                    |         |
| Hemoglobin (males)         | 14.0 – 18.0                  |         |
| Hemoglobin (females)       | 12.5 – 15.5                  |         |
| Hematocrit (males)         | 42.0 – 49                    |         |
| Hematocrit (females)       | 39.0 – 45                    |         |
| Platelets                  | 130 – 400 x 10^3             |         |
| Vitamin B12                | 190 – 920                    |         |
| Folic Acid                 | 125 – 600                    |         |
| HgA,C                      | 4 – 6.1                      |         |
Explanation of Lab results:

1. Total cholesterol, low-density lipoprotein (LDL) cholesterol, and triglycerides are the major fats in your bloodstream. High-density lipoprotein (HDL) cholesterol is also a blood fat that appears to protect against hardening of the arteries.

   **Total cholesterol (TC)**
   If TC less than 200:
   
   "Your cholesterol is in the normal range. We recommend a repeat in 5 years."

   If TC >200<239:
   
   "Your cholesterol may or may not be significantly high depending on the presence of other risk factors for heart disease (hypertension, obesity, tobacco use, diabetes, physical inactivity). Please follow up with your health care provider."

   If TC >240:
   
   Your cholesterol is elevated, and we recommend that you follow-up with your health care provider for further evaluation."

   **LDL Cholesterol (LDL)**
   IF LDL <100:
   
   "Your LDL cholesterol is normal, and we recommend a repeat in 5 years."

   If LDL 100-130:
   
   "Your LDL may be significant depending upon your medical history of heart disease. You should see your health care provider if you have a history of heart disease."

   If LDL 130-159:
   
   "Your LDL is elevated, however, you are not considered at risk for developing heart disease unless you have two or more additional cardiovascular risk factors (hypertension, obesity, tobacco use, diabetes, physical inactivity). If you already have heart disease or two of the listed risk factors, you should see your health care provider for further recommendations."

   If LDL >160:
   
   "Your LDL is significantly elevated, and you should see your health care provider for further recommendations."

   **HDL Cholesterol (HDL)**
   If HDL >35:
"Your HDL is normal. We recommend a repeat in 5 years."

If HDL <35:

"Your HDL is low and you may be at risk for cardiovascular disease. Please follow-up with your health care provider."

Triglycerides (TG)
If TG <220:

"Your triglycerides are normal."

If TG >220:

"Your triglycerides are elevated. Management options for elevations include diet and/or drug therapy depending on the presence of other risk factors. Please see your health care provider for further recommendations."

2. Creatinine
   The level of creatinine in your blood is an indirect measure of your kidney function.

   If in normal range:

   "Your creatinine is normal."

   If 1.4-2.5 (males) or 1.2-2.5 (females):

   "Your creatinine is in an elevated range which could mean that there is some decreased kidney function. We recommend that you see your health care provider to repeat the test and to provide further recommendations."

   If >2.5 (Participant was called and/or sent alert letter 7.2.1 or 7.2.2, and health care provider was called and/or send letter 7.2.4):

   "Your creatinine is significantly elevated, and we informed you previously to follow-up with your health care provider. Please follow-up with her/him if you have not already done so."

3. Fasting Glucose (FG)
   Glucose is your blood sugar and this value is used to evaluate for diabetes.

   If FG 74-126:

   "Your blood sugar is in the normal range."
If FG <60 (Participant and health care provider were called and/or received alert letter):

"Your blood sugar is below the normal range, and as notified previously you should see your health care provider. We recommend that you follow-up with her/him if you have not already done so."

If FG >200 (Participant and health care provider were called and received alert letters):

"Your blood sugar is significantly elevated and as recommended when we previously notified you of this abnormality you should follow-up with your health care provider. Please follow up with her/him if you have not already done so."

If FG >126<200:

"Your blood sugar is elevated and this could indicate the presence of diabetes. We recommend that you follow-up with your health care provider for a repeat level and further management option."

4. Sodium

Sodium is one of the essential electrolytes in the body. It is used as a measure of hydration (fluid balance) and electrolyte balance.

If within normal range:

"Your sodium is normal."

If >125  (Participant and health care providers were called and/or sent alert letters):

"Your sodium is significantly below the normal range and as noted in the previous letter sent to you, you should follow-up with your health care provider. Please follow-up with her/him if you have not already done so."

If >155  (Participant and health care provider were called and/or sent alert letter):

"Your sodium is significantly elevated and as noted in the previous letter sent to you, you should follow-up with your health care provider. Please follow-up with her/him if you have not already done so."

If <136>125 OR >146<155:

"Your sodium is abnormal (high or low) and this possibly is an indication of an electrolyte imbalance or altered hydration. Please see you health care provider for further recommendations."

5. Chloride

Chloride is one of the essential electrolytes in the body. It is used as a measure of hydration
(fluid balance) and electrolyte balance.

If in the normal range:

"Your chloride is normal."

If <80 OR >115 (Participant and health care provider were called and/or sent alert letter):

"Your chloride is significantly abnormal, and as previously notified you should follow-up with your health care provider. Please follow-up with her/him if you have not already done so."

If >80<98 OR >108<115:

"Your chloride is abnormal and could be an indication of an electrolyte imbalance or altered hydration. Please follow-up with your health care provider for further evaluation."

6. Potassium

Potassium is an essential electrolyte in the body. It is necessary for the body's general functioning.

If within normal range:

"Your potassium is normal."

If <3.2 OR >5.5 (Participant and health care provider were called and/or sent alert letter):

"Your potassium is significantly abnormal (high or low), and as previously notified you should follow-up with your health care provider. Please follow-up with her/him for further evaluation."

If <3.5>3.2 OR >5.1<5.5:

"Your potassium is abnormal and could be an indication of an electrolyte imbalance that requires further evaluation. Please follow-up with your health care provider."

7. Uric Acid

Uric acid is an end product of the body's metabolism. In some instances its elevation could indicate gout.

If in the normal range:

"Your uric acid is normal."

If >12 (Participant and health care provider were called and/or send alert letter):
"Your uric acid is significantly elevated, and as previously notified you should see your health care provider for further evaluation. Please follow-up with her/him if you have not already done so."

If >8.5<12 (males) OR >7.5<12 (females):

"Your uric acid is elevated, and this could be an indication of gout. Please see your health care provider for further evaluation."

8. **Hemoglobin and Hematocrit**

The hemoglobin and hematocrit are used to evaluate the amount of red blood cells in the body and to assess for anemia.

If within the normal range:

"Your hemoglobin and hematocrit are normal."

If hemoglobin <12 (males) OR <10 (females):

OR

Hematocrit <35 (males) OR <30 (females):

"Your hemoglobin and hematocrit are low and as previously notified you should follow-up with your health care provider for further evaluation. Please follow-up with her/him if you have not already done so."

If hematocrit >53 (males) OR >50 (females)—participant and health care provider are called and/or sent alert letter:

"Your hematocrit is abnormally high and as previously notified you should follow-up with your health care provider for further evaluation. Please follow-up with her/him if you have not already done so."

If hemoglobin <14>12 (males) OR <12>10 (females):

OR

Hematocrit <42>35 (males) OR <39>30 (females):

"Your hemoglobin and hematocrit are slightly abnormal. This could be an indication of anemia. Please follow-up with your health care provider."

9. **Platelets**

Platelets are blood components that aid in clotting.

If within normal range

"Your platelet count is normal."
If <50,000 OR >500,000 (Participant and health care provider are called and/or sent alert letter):

"Your platelet count is abnormal (high or low) and as previously notified, you should follow-up with your health care provider for further evaluation. Please follow-up with her/him if you have not already done so."

If <130,000 >50,000 OR >400,000 <500,000:

"Your platelet count is abnormal and could indicate a clotting problem. Please follow-up with your health care provider."

10. **Vitamin B12**

Vitamin B12 is an essential B vitamin. It is usually acquired through the diet. Deficiency of the vitamin can cause an array of symptoms including weakness, anemia and mental changes.

If within the normal range:

"Your B12 is normal."

If <150:

"Your B12 is abnormal and you should follow-up with your health care provider for further recommendations."

11. **Folic Acid**

Folic acid is an essential nutrient in the body. It is usually acquired through the diet. A deficiency can cause anemia and has been implicated in certain birth defects.

If in normal range:

"Your folic acid is normal."

If <100:

"Your folic acid is low and you should follow-up with your health care provider for further recommendations."

12. **Hemoglobin A1C**

Hemoglobin A1C is used to assess control of blood sugar over an average of 3 months. Health care providers use it as a tool for management of diabetes.

If within normal range:

"Your hemoglobin A1C is normal."
If >7:

"Your hemoglobin A1C indicates less than optimal control of your blood sugar. Please follow-up with your health care provider."

13. **24-hr Urine Protein**

The presence of protein in the urine can be an indicator of early kidney disease, especially in persons with diabetes.

If >150:

"Your 24-hr urine collection revealed the presence of protein in your urine. As this could indicate early kidney disease, especially if you have diabetes, we recommend that you follow-up with your health care provider."

**NOTE**

If **any** values are abnormal, the participant and her/his health care provider are sent an abnormal results cover letter (7.3.3, 7.3.4 or 7.3.6).

If **all** values are normal the participant and health care provider are sent a normal results cover letter (7.3.1, 7.3.2 or 7.3.5).

The information included on the participant's Results Report Summary will consist of the brief explanation of each specific analyte and **only** the text in bold type that applies to the specific participant.
A preliminary report of your lung function is shown below. A final report will be sent to your health care provider with the test results.

Test was not performed or lung function could not be determined accurately.

Results:

<table>
<thead>
<tr>
<th>Lung Function Test</th>
<th>Your Value</th>
<th>Usual Normal Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>FVC</td>
<td></td>
<td>of Predicted</td>
</tr>
<tr>
<td></td>
<td></td>
<td>80% and greater</td>
</tr>
<tr>
<td>FEV1</td>
<td>...............</td>
<td>of Predicted</td>
</tr>
<tr>
<td></td>
<td></td>
<td>80% and greater</td>
</tr>
<tr>
<td>FEV1/FVC</td>
<td></td>
<td>of Predicted</td>
</tr>
<tr>
<td></td>
<td></td>
<td>65% and greater</td>
</tr>
</tbody>
</table>

FVC is the total amount of air you blew out of your lungs. FEV1 is the amount of air you were able to blow out in the first second. FEV1/FVC is the ratio of the two volumes.

If the values are within the normal range or above, your lung function is normal.

If these values are below the usual range, your lung function is somewhat below normal. About 5% of healthy people have values just below the normal range.

If either FVC or FEV1 are less than 50% of your predicted normal value, or if your FEV1/FVC ratio is less than 50%, your function is substantially reduced. If you and your health care provider were unaware of this, you should see s/he soon for evaluation.
Appendix 2.3  Schedule of Results Reporting

SCHEDULE FOR REPORTING YOUR JHS RESULTS

AT THE END OF YOUR CLINIC VISIT YOU WILL RECEIVE A SUMMARY OF:

HEIGHT AND WEIGHT
BLOOD PRESSURE
ELECTROCARDIAGRAM (PRELIMINARY REPORT)
PULMONARY FUNCTION TEST (PRELIMINARY REPORT)

YOUR TESTS WILL BE SENT TO SPECIALIZED LABORATORIES FOR MEASUREMENTS AND INTERPRETATIONS. APPROXIMATELY 6 TO 8 WEEKS AFTER YOUR VISIT DATE, A FULL SUMMARY WILL BE REPORTED TO YOU AND YOUR HEALTH CARE PROVIDER. IT WILL INCLUDE THE FOLLOWING:

HEIGHT AND WEIGHT     CAROTID ULTRASOUND
BLOOD PRESSURE         ECHOCARDIOGRAM
ELECTROCARDIAGRAM       PULMONARY FUNCTION TEST

BLOOD TESTS:

FASTING GLUCOSE, SODIUM, POTASSIUM, CHLORIDE, URIC ACID, B12, FOLATE, TOTAL CHOLESTEROL, LDL CHOLESTEROL, HDL CHOLESTEROL, TRIGLYCERIDES, CREATININE, HEMOGLOBIN A1C, HEMATOLOGY WHICH INCLUDES: HEMOGLOBIN (HGB), HEMATOCRIT (HCT), PLATELETS

URINE TESTS: (24-HR) PROTEIN
Appendix 2.4  Participant: Referral post clinic visit with health care provider designated

Date

Participant’s name
Participant’s address

Dear Mr./Mrs./Ms.______:  
We would like to thank you for your visit to the Jackson Heart Study Exam Center on VISIT DATE. Since your examination, we have obtained some results of your studies. In order for all Jackson Heart Study participants to get the best medical care, we would like to let you know that your exam results revealed a finding that should be discussed with your health care provider. A report of the finding is enclosed.

As you requested, we have sent a copy of these results to PROVIDER’S NAME. We suggest that you contact her/him as indicated on the enclosed results report to determine how to follow-up on these results.

Should you have any questions, please feel free to contact us at 815-5050. A report of your additional test results will be sent when available.

Sincerely,


MD
Enclosure
Appendix 2.5  Participant: Referral post clinic visit without designated health care provider

Date

Participant’s name
Participant’s address

Dear Mr./Mrs./Ms.________:

Since your examination at the Jackson Heart Study Exam Center on VISIT DATE we have obtained some results of your studies. Your results revealed a finding that should be discussed with your health care provider. A report of the finding is enclosed.

Because the Jackson Heart Study does not provide any clinical diagnosis or treatment, we offer to send all relevant information to participants’ usual source of medical care. During your visit you did not designate a health care provider. If you do not have a personal health care provider, and would like assistance in finding one, please call the Jackson Heart Study office at 815-5050 for provider referral information.

Should you have any questions, please feel free to contact us at 815-5050. A final report with results of your additional tests will be forwarded when available.

Sincerely,

MD
Enclosure
Appendix 2.6  Health Care Provider: Referral at clinic visit

Date

Health care provider’s name
Health care provider’s address

Dear PROVIDER:

We saw your patient, PATIENT’S NAME, in the Jackson Heart Study Exam Center on VISIT DATE. During the course of our evaluation, the following abnormality was identified. We believe that this requires your attention.

**ABNORMAL RESULT**

The Jackson Heart Study does not provide diagnosis, medical advice, or treatment. We have recommended to Mr./Mrs./Ms. PATIENT’S NAME that s/he contact you to determine how to follow-up on these results.

Should you have any questions, please feel free to contact us at 815-5050. A final report with results of our tests will be forwarded when available.

Sincerely,

MD
Appendix 2.7 Health Care Provider: Referral post clinic visit

Date

Provider's name
Provider's address

Dear PROVIDER'S NAME

We saw your patient, PATIENT'S NAME, in the Jackson Heart Study Exam Center on VISIT DATE. Since that exam we have obtained some results that revealed a finding that we think requires your attention. A report of the finding(s) is enclosed.

The Jackson Heart Study does not provide diagnosis, medical advice, or treatment. We have recommended to Mr./Mrs./Ms. PATIENT'S NAME that s/he contact you to determine how to follow-up on these results.

Should you have any questions, please feel free to contact us at 815-5050. A final report of additional results will be sent when available.

Sincerely,

MD
Enclosure
Appendix 2.8  Participant: Normal results with health care provider designated

Date

Participant’s name
Participant’s address

Dear Mr./Mrs./Ms.____________:

Thank you for taking part in the Jackson Heart Study examination at our Exam Center on VISIT DATE. We appreciate your willingness to participate in this important study.

The results of your examination are summarized on the enclosed report. We are pleased to report that no abnormalities were found.

Because the Jackson Heart Study does not provide any clinical diagnosis or treatment, we offer to send all relevant information to participants’ usual sources of medical care. According to your instructions during your Jackson Heart Study visit, we have mailed these results to PROVIDER’S NAME for her/his review.

Thank you again for being a member of the Jackson Heart Study.

Sincerely,

MD
Enclosure
Appendix 2.9  Participant: Normal results without health care provider designated

Date

Participant’s name
Participant’s address

Dear Mr./Mrs./Ms.________:

Thank you for taking part in the Jackson Heart Study examination at our Exam Center on VISIT DATE. We appreciate your willingness to join in this important study.

Because the Jackson Heart Study does not provide any clinical diagnosis or treatment, we offer to send any relevant information to participants’ usual source of medical care. During your visit you did not designate a health care provider.

The results of your examination are summarized on the enclosed report. No abnormalities were found during the Jackson Heart Study examination. If you find that the enclosed report is not clear, please call us at 815-5050.

Thank you again for being a member of the Jackson Heart Study.

Sincerely,

MD
Enclosure.
Appendix 2.10 Participant: Abnormal results with health care provider designated without prior alert/referral

Date

Participant’s Name
Participant’s address

Dear Mr./Mrs./Ms.________________:

Thank you for taking part in the Jackson Heart Study examination at our Exam Center on VISIT DATE. We appreciate your willingness to participate in this important study.

The results of your examination are summarized on the enclosed report. One or more of the measurements, as indicated on the report, should be reviewed by your health care provider to determine if further evaluation is needed.

As you instructed during your visit, we have mailed these results to PROVIDER’S NAME. Because the Jackson Heart Study does not provide any clinical diagnosis or treatment, we suggest that you contact PROVIDER’S NAME for any additional recommendations.

Thank you again for being a member of the Jackson Heart Study.

Sincerely,

MD
Enclosure
Appendix 2.11 Participant: Abnormal results with health care provider designated with prior alert/referral

Date

Participant’s name
Participant’s address

Dear Mr./Mrs./Ms.__________:

Thank you for taking part in the Jackson Heart Study examination at our Exam Center on VISIT DATE. We appreciate your willingness to participate in this important study.

The results of your examination are summarized on the enclosed report. One or more of the measurements, as shown on the report, should be reviewed by your health care provider to determine if further evaluation is needed.

As instructed during your visit, we have mailed these results to PROVIDER’S NAME, and have previously reported alerts to you and PROVIDER’S NAME. We are now sending a final report. Because the Jackson Heart Study does not provide any clinical diagnosis or treatment, we suggest that you contact PROVIDER’S NAME for further recommendations.

Thank you again for being a member of the Jackson Heart Study.

Sincerely,

MD
Enclosure
Appendix 2.12 Participant: Abnormal results with no health care provider designated

Date

Participant’s name
Participant’s address

Dear Mr./Mrs./Ms.________:

Thank you for taking part in the Jackson Heart Study examination at our Exam Center on VISIT DATE. We appreciate your willingness to join this important study.

The results of your examination are summarized on the enclosed report. We have indicated the results that are abnormal. In many instances such results do not have serious implications; however, we recommend that your results be reviewed by a health care provider to determine if further evaluation is needed.

Because the Jackson Heart Study does not provide any clinical diagnosis or treatment, we offer to send any relevant information to participants’ usual health care provider. During your visit you did not designate such a provider. If you do not have a personal health care provider and you would like assistance in finding one please call the JHS office at 815-5050 for provider referral information.

Thank you again for being a member of the Jackson Heart Study.

Sincerely,

MD
Enclosure
Appendix 2.13 Health Care Provider: Normal results

Date

Provider’s name
Provider’s address

Dear PROVIDER’S NAME:

Your patient, PATIENT’S NAME, is a participant in the Jackson Heart Study and was seen at our Exam Center on VISIT DATE. Enclosed is a summary report of her/his results.

The Jackson Heart Study routinely offers to send all clinically relevant data to the participant’s health care provider. PATIENT’S NAME has requested that we send the results to you, and we have also sent a report to her/him. No clinically relevant abnormalities were found in any areas evaluated by the Jackson Heart Study.

The Jackson Heart Study examination procedures are designed exclusively for epidemiological research. Our study procedures do not substitute for a clinical examination, nor does the study provide any diagnoses or treatment. If a condition or laboratory test result is found to require diagnostic confirmation or possible treatment, the study participant is referred to her/his source of medical care.

Should you have any questions, please feel free to contact us at 815-5050. A final report of additional results will be sent when available.

Thank you for your support.

Sincerely,

MD
Enclosures
Appendix 2.14 Health Care Provider: Abnormal results without prior alert/referral

Date

Provider’s name
Provider’s address

Dear PROVIDER:

Your patient, PATIENT’S NAME, is a participant in the Jackson Heart Study and was seen at our Exam Center on VISIT DATE. Enclosed is a report of the results of this examination. We have indicated the abnormalities.

The Jackson Heart Study routinely offers to send all clinically relevant data to the participant’s health care provider. PATIENT’S NAME has requested that we send the results to you. We have notified PATIENT’S NAME of the abnormalities, and have suggested that s/he contact you to determine if further evaluation is needed.

The Jackson Heart Study examination procedures are designed exclusively for epidemiological research. Our study procedures do not substitute for a clinical examination, nor does the study provide any diagnostic confirmation or possible treatment. The participant is referred to her/his usual source of medical care.

Should you have any questions, please feel free to contact us at 815-5050. A final report of additional results will be sent when available.

Thank you for your support.

Sincerely,

MD
Enclosure
Appendix 2.15 Health Care Provider: Abnormal results with prior alert/referral

Date

Provider’s name
Provider’s address

Dear PROVIDER’S NAME:

Your patient, PATIENT’S NAME, is a participant in the Jackson Heart Study, and was seen at our Exam Center on VISIT DATE. Enclosed is our final report of the results of this examination. We have indicated the abnormalities.

The Jackson Heart Study routinely offers to send all clinically relevant data to the participant’s health care provider. PATIENT’S NAME has requested that we send these results to you, and we have already reported to you her/his earlier alerts. We are also sending a final report to PATIENT’S NAME indicating the abnormalities and reminding her/him to contact you if s/he hasn’t done so.

The Jackson Heart Study examination procedures are designed exclusively for epidemiological research. Our study procedures do not substitute for a clinical examination, nor does the study provide any diagnostic confirmation or possible treatment. The participant is referred to her/his usual source of medical care.

Should you have any questions, please feel free to contact us at 815-5050. A final report of additional results will be sent when available.

Thank you for your support.

Sincerely,

MD

Enclosures
Appendix 2.16 Cover Letter for transmission to a Third Party

Date

Company’s/recipient’s name
Company’s/recipient’s address

Dear Sir:

The enclosed information is provided to COMPANY’S/RECIPIENT’S NAME, per a written request dated DATE OF REQUEST and signed by PARTICIPANT’S NAME, a Jackson Heart Study participant. This is a copy of the information provided on DATE OF RESULTS REPORT to PARTICIPANT’S NAME and her/his health care provider.

The enclosed report represents part of the study results obtained during the Jackson Heart Study clinic visit on VISIT DATE. The Jackson Heart Study does not offer medical diagnoses or treatment. Any findings of medical relevance are, however, shared with the study participant and her/his health care provider. The additional information collected by the Jackson Heart Study represents data of research interest only.

Should you have any questions, please feel free to contact us at 815-5050. A final report of additional results will be sent when available.

Sincerely,

MD
Enclosures
Appendix 2.17 Participant: Abnormal ECG results with health care provider designated

Date

Participant’s name
Participant’s address

Dear Mr./Mrs./Ms._______:

Since you Jackson Heart Study clinic exam on VISIT DATE we have obtained an official interpretation of your electrocardiogram (EKG). The interpretation has revealed a finding that we think should be discussed with your health care provider. A copy is enclosed.

Some EKG findings might be considered insignificant once a comparison with previous EKG’s is made and your clinical history and findings are evaluated by your health care provider. We have, therefore, forwarded a copy of these results to PROVIDER’S NAME, the provider to whom you requested we send your results.

Should you have any questions, please feel free to contact us at 815-5050. A final report with results of your additional tests will be forwarded when available.

Sincerely,

MD
Enclosure
Appendix 2.18 Participant: Abnormal ECG results without health care provider designated

Date

Participant’s name
Participant’s address

Dear Mr./Mrs./Ms.________:

Since you Jackson Heart Study clinic exam on VISIT DATE we have obtained an official interpretation of your electrocardiogram (EKG). The interpretation has revealed a finding that we think should be discussed with your health care provider. A copy is enclosed.

Some EKG findings might be considered insignificant once a comparison with previous EKG’s is made and your clinical history and findings are evaluated by your health care provider. If you do not have a health care provider and would like assistance in finding one, please call the JHS office at 815-5050 for provider referral information.

Sincerely,

MD
Enclosure
Appendix 2.19 Health Care Provider: Abnormal ECG results

Dear PROVIDER’S NAME:

Your patient, PATIENT’S NAME, is a participant in the Jackson Heart Study, and was seen at our Exam Center on VISIT DATE. Since that time we have obtained an official interpretation of her/his EKG and think that there are findings that require your attention. We have enclosed a copy of the EKG and a copy of the letter sent to PATIENT’S NAME.

The Jackson Heart Study does not provide diagnoses, medical advice, or treatment. We have recommended to PATIENT’S NAME that s/he contact you to determine how to follow-up on the findings.

Should you have any questions, please feel free to contact us at 815-5050. A final report of additional results will be forwarded when available.

Sincerely,

MD
Enclosures
Appendix 2.20 Participant: Abnormal Carotid Ultrasound result with health care provider designated

Date

Participant’s name
Participant’s address

Dear Mr./Mrs./Ms.____________:

Since your JHS clinic exam on VISIT DATE we have obtained additional results of your studies. The evaluation of your ultrasound study at our reading center revealed a finding that should be discussed with your health care provider.

A narrowing of one of the blood vessel in your neck was found. Such narrowing is most often associated with hardening of the arteries. While some narrowing is found in many people, the amount of narrowing identified in your study was greater than expected. Because the Jackson Heart Study carotid ultrasound examination performed on you is a limited study and the measurements obtained are of research value only, we recommend that you see your health care provider for further evaluation through a more clinically-focused study.

As you requested during your visit, we have forwarded a copy of these results to PROVIDER’S NAME. Should you have any questions, please feel free to contact us at 815-5050. A final report of your additional tests will be forwarded when available.

Sincerely,

MD
Appendix 2.21 Participant: Abnormal Carotid Ultrasound results without health care provider designated

Date

Participant’s name
Participant’s address

Dear Mr./Mrs./Ms.________________:

Since your JHS clinic exam on VISIT DATE we have obtained additional results of your studies. The evaluation of your ultrasound study at our reading center revealed a finding that should be discussed with your health care provider.

A narrowing of one of the blood vessel in your neck was found. Such narrowing is most often associated with hardening of the arteries. While some narrowing is found in many people, the amount of narrowing identified in your study was greater than expected. Because the Jackson Heart Study carotid ultrasound examination performed on you is a limited study and measurements obtained are of research value only, obtaining a more complete, clinically-focused study is recommended. We recommend that you see your health care provider for this study.

If you do not have a health care provider or would like assistance in finding one, please call the JHS office at 815-5050.

Should you have further questions, please feel free to contact us. A final report with your additional test results will be forwarded when available.

Sincerely,

MD
Enclosure
Appendix 2.22 Health Care Provider: Abnormal Carotid Ultrasound results

Date

Health care provider’s name
Health care provider’s address

Dear HEALTH CARE PROVIDER:

Your patient, PATIENT’S NAME, is a participant in the Jackson Heart Study and was seen at our Exam Center on VISIT DATE. During the course of the B-mode ultrasound examination of the carotid arteries the enclosed findings were identified. We think that these findings require your attention. We have also enclosed a copy of the letter sent to your patient.

The Jackson Heart Study does not provide diagnosis, medical advice, or treatment. We have recommended to PATIENT’S NAME that s/he contact you to determine how to follow-up on these results. Because the JHS carotid ultrasound examination performed on your patient is a limited study and measurements obtained are of research value only, obtaining a more complete, clinically-focused carotid ultrasound is recommended.

Should you have any questions, please feel free to contact us at 815-5050. A final report of additional results will be forwarded when available.

Sincerely,

MD
Enclosures
Appendix 2.23 Participant: Abnormal Echocardiogram results with health care provider designated

Date

Participant’s Name
Participant’s address

Dear Mr./Mrs./Ms.____________: 

Since your examination at the Jackson Heart Study exam center on VISIT DATE, we have obtained additional results of your studies. The evaluation of your echocardiogram by the echocardiogram reading center cardiologist has revealed a finding that we think should be discussed with your health care provider. A copy of the report is enclosed.

(Ejection Fraction Alert)

Your left ventricular ejection fraction was less than 30%. This is an indication that your heart isn’t pumping at an optimum level. We recommend that you consult your health care provider to determine whether further evaluation or treatment is necessary.

(Aortic Aneurysm Alert)

Your echocardiogram shows that the large artery (aorta) that leads from your heart has an aneurysm, which is an out-pouching of the vessel’s wall. Depending on its size and your medical history this may or may not be significant. We recommend that you consult your health care provider to determine whether further evaluation or treatment is necessary.

(Left Ventricular Enlargement Alert)

Your echocardiogram pictures show that one of the large chambers of your heart is larger than the size that is accepted as normal. This enlargement can have medical significance; thus, we recommend that you consult your health care provider to determine whether further evaluation or treatment is necessary.

(Aortic Stenosis Alert)

The valve that regulates blood flow out of the heart and into the aorta (the large vessel through which blood is carried to parts of the body) has an abnormal narrowing that is possibly significant. We recommend that you consult your health care provider to determine whether evaluation or treatment is needed.

As you instructed during your Jackson Heart Study visit, we have forwarded a copy of these results to PROVIDER’S NAME. Should you have any questions please feel free to contact us at 815-5050. A final report with additional test results will be forwarded when available.

Sincerely,

MD
Enclosures
Appendix 2.24 Participant: Abnormal Echocardiogram results without health care provider designated

Date

Participant's name
Participant's address

Dear Mr./Mrs./Ms.____________:

Since your examination at the Jackson Heart Study exam center on VISIT DATE, we have obtained additional results of your studies. The evaluation of your echocardiogram by the echocardiogram reading center cardiologist has revealed a finding that we feel should be discussed with your health care provider. A copy of the report is enclosed.

(Ejection Fraction Alert)

Your left ventricular ejection fraction was less than 30%. This is an indication that your heart isn't pumping at an optimum level. We recommend that you consult your health care provider to determine whether further evaluation or treatment is necessary.

(Aortic Aneurysm Alert)

Your echocardiogram shows that the large artery (aorta) that leads from your heart has an aneurysm, which is an out-pouching of the vessel's wall. Depending on its size and your medical history this may or may not be significant. We recommend that you consult your health care provider to determine whether further evaluation or treatment is necessary.

(Left Ventricular Enlargement Alert)

Your echocardiogram pictures show that one of the large chambers of your heart is larger than the size that is accepted as normal. This enlargement can have medical significance; thus, we recommend that you consult your health care provider to determine whether further evaluation or treatment is necessary.

(Aortic Stenosis Alert)

The valve that regulates blood flow out of the heart and into the aorta (the large vessel through which blood is carried to parts of the body) has an abnormal narrowing that is possibly significant. We recommend that you consult your health care provider to determine whether further evaluation or treatment is necessary.

If you do not have a personal health care provider or would like assistance in finding one, please call the JHS office at 815-5050. Should you have further questions, please feel free to contact us. A final report with your additional test results will be forwarded when available.

Sincerely,

MD
Appendix 2.25 Health Care Provider: Abnormal Echocardiogram results

Date

Provider's name
Provider's address

Dear PROVIDER:

We saw your patient, PATIENT’S NAME, in the Jackson Heart Study exam center on VISIT DATE. During the echocardiogram evaluation the enclosed findings were identified. We feel that this needs further evaluation. Also enclosed is a copy of the letter sent to your patient.

The Jackson Heart Study does not provide diagnosis, medical advice, or treatment. We have recommended to PATIENT’S NAME that s/he contact you to determine how to follow-up on these results.

Should you have any questions, please feel free to contact us at 815-5050. A final report of additional results will be forwarded when available.

Sincerely,

MD
Enclosures
Appendix 2.26 Participant: Abnormal Pulmonary Function results with health care provider designated

Date

Participant’s name
Participant’s address

Dear Mr./Mrs./Ms.____________:

During your Jackson Heart Study examination on VISIT DATE you underwent a study to evaluate your lung function. You received a preliminary report at the conclusion of your exam. A final report is now available. A copy is enclosed for you and one is being sent to your health care provider. Because your values indicate that your lung function is below that normally predicted for your age, height, and sex we recommend that you contact your health care provider for further evaluation.

Should you have any questions, please feel free to contact us at 815-5050. A final report with results of your additional tests will be forwarded when available.

Sincerely,

MD
Enclosures
Appendix 2.27 Participant: Abnormal Pulmonary Function results without health care provider designated

Date

Participant’s name
Participant’s address

Dear Mr./Mrs./Ms.__________:

During your Jackson Heart Study exam on VISIT DATE you underwent a study to evaluate your lung function. You received a preliminary report at the conclusion of your exam. A final report is now available, and a copy is enclosed.

Because your values indicate that your lung function is below that normally predicted for your age, height, and sex we recommend that you follow-up with your health care provider. If you do not have a health care provider or would like assistance finding one, please call the JHS office at 815-5050 for provider referral information.

Should you have any questions, please feel free to contact us. A final report of additional results will be forwarded when available.

Sincerely,

MD
Enclosures
Appendix 2.28 Health Care Provider: Abnormal Pulmonary Function results

Dear PROVIDER’S NAME:

We saw your patient, PATIENT’S NAME, in the Jackson Heart Study exam center on VISIT DATE. At that time s/he underwent Pulmonary Function Tests. Enclosed is a final report from the PFT Reading Center. It indicates the findings that we feel need your attention. Also enclosed is a copy of the letter sent to your patient.

The Jackson Heart Study does not provide diagnosis, medical advice or treatment. We have recommended to PATIENT’S NAME that s/he contact you to determine how to follow-up on these results.

Should you have any questions, please feel free to contact us at 815-5050. A final report of additional results will be forwarded when available.

Sincerely,

MD
Enclosures
APPENDIX 3: FOLLOW-UP AND PARTICIPANT RETENTION
Appendix 3.1 Prototype Participant Letter: Notification of Forthcoming Annual Follow-up Interview

Dear Mr./Mrs./Ms. ____________________________:

It has been almost one year since you were contacted by the Jackson Heart Study, the medical research project conducted by Jackson State University, Tougaloo College and the University of Mississippi Medical Center and sponsored by the National Institutes of Health and the Office of Research for Minority Health in which you are participating. As explained at your first examination, the JHS calls each year to monitor the health of its participants.

In the next few days a JHS interviewer will telephone you to obtain some brief information about your health in the past year. It would be helpful if you could have ready for the interviewer information about any hospitalizations or illnesses you may have had in the past year. The interview will take about 20 minutes.

If you think it will be difficult for us to reach you in the next week, please telephone the JHS office at (601) 815-5050 so that we can make special arrangements for your interview.

We thank you again for your assistance in this research project.

Sincerely,

(Principal Investigator)
Appendix 3.2  Recommendations from the JHS Participant Recruitment Study

(SEE FOLLOWING PAGES)
<table>
<thead>
<tr>
<th>Interpreting Concerns: Double Consciousness</th>
<th>1. Including selected real life situations based on building trust in staff applicant interviews. Situations could be role played during the interview process with actual volunteer cohort members who would assist in developing the criteria for hiring.</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Involving persons from the community in the interviewer selection and training process to assure that the nuances of culturally appropriate communication and discernment practices are woven throughout the training process for all staff.</td>
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<tr>
<td>3. Including statements reflective of the prerequisites for engendering the trust of potential JHS cohort members in position qualifications for a JHS Research Associate (recruiter or clinic staff).</td>
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<tr>
<td>4. Assuring that the stories, interpretations and implications from this final report are known and used by the Director of Recruitment and Clinic Director in designing all staff training, continuing education and counseling.</td>
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<tr>
<td>5. Holding regular collaborative feedback sessions among interviewers to share interviewing experiences and strategies that work which would expand their individual skills.</td>
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<td>6. Hosting an annual JHS Research Day where interviewers, as partners in the research endeavor, contribute their collective wisdom to the JHS community.</td>
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<tr>
<td>Interpreting Concerns: Informed Consent</td>
<td>7. Recruiting clinic staff from the Jackson African-American community could provide a context in which participants might feel more comfortable asking questions and expressing concerns about the study.</td>
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<tr>
<td>8. Training clinic staff with community input to focus on issues of sensitivity in the consent</td>
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<td>Process and openness to discerning the best method of presentation for each participant could increase participation levels.</td>
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</table>

| Gathering the JHS Family: Participants and Community as Co-Investigators | 9. Training recruiters and interviewers with the assistance of community co-investigators. |

| Gathering the JHS Family: Recruiting AS Finding Common Ground | 10. Community co-involvement in developing criteria and job descriptions through membership in the Recruiter Selection and Training Committee. |
| 11. Hiring of recruiters to assure a “good mix” not only of ethnicity but of age and gender. |
| 12. Hiring recruiters who are dedicated to the project and its importance—people persons who are friendly, sincere and personable. |
| 13. Using stories from interviews as part of training. As in the exemplar of the participant’s reflection on being asked to participate, the story would be interpreted in several ways with practical training in what might happen in recruiting with each interpretation. |
| 14. Including interactive experiences during training sessions with volunteer ARIC participants (or other community volunteers who serve on the Recruitment Selection and Training Committee) to gain practical experience in interviewing as listening. |

| Gathering the JHS Family: Recruiting AS Storytelling | 15. Training in narrative approaches to explain the study using paradigm stories in the voices of others who have experienced study participation. |
| 16. Including stories of participation in Web sites, brochures, newsletters and in personal communications with the community. |

| Gathering the JHS: Overcoming Barriers | 17. Training staff to recognize and connect JHS participants with potential health care or social needs with the JHS social worker. This would ensure that needy persons could be |
linked with available resources, for example the newly developed state health program that guarantees free health care for those who have no way of paying for it.

<table>
<thead>
<tr>
<th>B. A community-driven model to inform contacts in the field</th>
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</thead>
<tbody>
<tr>
<td>1. Approaching potential participants in the field, a community-driven model might mean...</td>
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<table>
<thead>
<tr>
<th>Interpreting Concerns: Informed Consent for Genetic Studies</th>
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<tbody>
<tr>
<td>1. Safeguarding concerns by being up front about the inclusion of genetic testing in the study and in the consent process.</td>
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<tr>
<th>Calling Participation: Strategies of Recruiting</th>
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<tr>
<td>2. Articulating clearly the range of BOTH the values and benefits AS WELL AS the disadvantages and dangers of research participation for culturally situated decision making about joining. An <strong>in-home video tape</strong> that shows what the JHS involves told by persons who have taken part in ARIC is one possibility.</td>
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<tr>
<th>Gathering the JHS Family: A Community Driven Model</th>
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<tbody>
<tr>
<td>3. Developing a core of ARIC volunteers to serve as the <strong>JHS Council of Elders</strong> of community members as well as elders from the JHS research community and participating institutions. In addition to advising the recruitment team, they might provide information as well as instrumental and emotional support for participants at each phase of the study. For example, could an elder poet from Jackson State University preserve the heart of the JHS?</td>
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<tr>
<th>Gathering the JHS Family: Recruiting AS Finding Common Ground</th>
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<tbody>
<tr>
<td>4. Matching recruiters with those being recruited. For example, when recruiting older persons, sending a more “seasoned” individual who can connect with some of their life realities.</td>
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</table>

| | 5. Sending teams of recruiters of mixed ethnicity, age or gender. When this is not possible, follow up with recruiter of different ethnicity (age or gender) to assure that the decision not to participate was not based on the messenger. |
| 6. Providing clear identification of all recruiters which is well known to the community--uniform clothing and JHS identification used on each contact with clear information on how to contact the JHS office and other ways to validate who the person is. This would extend to all persons involved in the project, e.g. taxi drivers would have appropriate JHS identification to provide assurances to persons being transported that they were “on the up and up.” |
## B. A community-driven model to inform contacts in the field

2. A community-driven model might also mean specific strategies of recruiting which enact African-American family values of storytelling and helping out...

| Gathering the JHS Family: Recruiting AS Storytelling | 1. Giving voice to the study through story. For example, the convincing conversation instead of being examples or descriptors of a study of hypertension and heart disease might be a story about hypertension or heart disease that shows the “bottom line” of health benefits. A recruiter might turn the experiences we have heard from interpretive interviews into scripts or “story lines” for recruiting.  
  “Let me tell you about someone just like you. This is a story of a woman who was in the ARIC study for the last twelve years. She says: ...... [insert example story].” |
| --- | --- |
| Gathering the JHS Family: Recruiting THROUGH the Friendship Tree | 2. Developing multi-level friendship networks or “extended family units” in neighborhoods, at the work site, and so forth to mutually support each other in study participation.  
3. Offering the availability of the JHS Elders volunteer corps to potential or new recruits for questions, assistance, transportation. For example, we have incorporated a question in the Eligibility Form which advises potential participants of this volunteer group and offers to someone get in touch if the participant chooses.  
4. Focusing recruiting in targeted segments of the sampling area for a designated period of time to allow teams of volunteers--students, church members, neighborhood groups--who are providing a community service to saturate the area with information. Recruiters would follow within a set time frame to actively recruit the identified sample in that area. |

## B. A community-driven model to inform contacts in the field

3. A community-driven model might include strategies of retaining participation which build and
sustain a “home” for the JHS family...

<table>
<thead>
<tr>
<th>Welcoming and Staying: Creating Space and Place for the JHS</th>
<th>1. A building that reflects the caring of the JHS is a clean, welcoming space that again and again is attended to and kept that way over time.</th>
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<tbody>
<tr>
<td>2. An organization that lives up to its promises of respecting people’s time.</td>
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<tr>
<td>3. Involving ALL the researchers in recruiting by having at least one night a month where investigators accompany the recruitment team to invite participation.</td>
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<td>4. Scheduling recruiters to spend time in the clinic each week welcoming participants they have recruited and provide a continuing connection.</td>
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<td>5. Engaging in small acts of caring in ALL PHASES of the study--respectful recognition of personhood including direct eye contact, calling by name including proper title and salutations, never assuming the familiar.</td>
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<td>6. Making time and opportunity for listening to community stories.</td>
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<td>7. Sending birthday, Kwanzaa, or other holiday cards to all study participants each year as a remembrance during special times of the year.</td>
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<td>8. Making reminder calls in advance of clinic visits.</td>
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<td>9. Sending thank-you letters following each study contact for home induction, clinic or annual follow-up calls.</td>
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<tr>
<td>10. Offering people tangible incentives of appreciation for their efforts. For some this might be monetary; for others a selection of things which would appeal to differing age and social groups. For example, gift certificates for restaurants or other local businesses or other small mementoes which remind persons of their membership in the study. All participants should leave the JHS examination clinic with some small token which reminds them of the study and of heart health (for example, a card of heart attack or stroke warning signs with the JHS logo; a JHS container with one aspirin to take with onset of symptoms).</td>
<td></td>
</tr>
<tr>
<td>Welcoming and Staying: Overcoming Barriers</td>
<td>11. Providing each participant with a certificate of membership in the JHS cohort which is suitable for framing.</td>
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<td>12. Flexible scheduling to accommodate busy schedules. While the demands of the study protocol (fasting) require early morning times, offering Saturday appointments as well as working with persons who may have to cancel multiple times before actually completing their visit could make all the difference.</td>
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<td>13. Negotiating with businesses, White and Black, to provide support for paid time off for participants to attend study visits and to accommodate the completion and pick up of the 24 hour ambulatory monitoring measures.</td>
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<td>14. Providing child care and transportation, if needed.</td>
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<td>15. Negotiating with health and social care providers to provide special access for JHS participants which might range from providing a free medical visit to connecting with medical assistance programs to assist in meeting health needs.</td>
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<td></td>
<td>16. Providing opportunities for participants to return to the clinic to discuss the results of their examination once all blood and other results are returned.</td>
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</table>

C. A community-driven model to inform involving the community in ongoing oversight and monitoring of recruitment and retention efforts...

<table>
<thead>
<tr>
<th>Gathering the JHS Family: Participants and Community as Co-investigators</th>
<th>1. Developing an <strong>Oversight and Evaluation Committee</strong> comprised of community members that meets bi-annually to go over the evaluations from the study participants and suggest ways to improve or change interactions with co-participants and the conduct of the study.</th>
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<tr>
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<td>2. Co-writing the Manual of Operations and Training Manuals for participant recruitment as well as examinations and interviews.</td>
</tr>
<tr>
<td>Gathering the JHS Family: Recruiting AS</td>
<td>3. Continuing of the interpretive component of the PRS as an ongoing aspect of the recruitment and retention plan such that staff automatically refer situations of particular</td>
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M2V1.0_Appendices_02-26-2001
Finding Common Ground

1. Using a wide variety of media and person to person contact to disseminate information and raise awareness of the JHS.

2. Sponsoring a weekly radio show which airs at dinner time perhaps on Jackson State University’s radio station, **JHS Family Tales at the Table**. For each show, a community leader might be invited to read a compelling African-American story that gathers family into conversation. Perhaps the Jackson State University literature department could develop this program. Before the story is presented, a brief celebration of the accomplishments of JHS members could be given. Community leaders could be self or other nominated and selected by the radio station to represent children, adults and elders who are esteemed by their communities. After the story is done, questions could follow, perhaps one or two that would spark thinking.

4. Placing a “suggestion box” in a prominent location in the clinic so that participants can comment on their visit and staff interactions.

5. Following up on study contacts with study satisfaction questionnaires, the content of which is hermeneutically co-designed with the community.

6. Providing a study “hot line” where any compliments, complaints, or suggestions can be addressed and advertise it widely to all participants (and staff alike!).

7. Hearing suggestions for improvement from a community evaluation group who meet biannually to review progress in recruitment and retention and evaluation comments.

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II. On a Foundation of Community Partnerships Assuring Multiple Paths to Participation in the JHS using...

A. A community-driven model to inform growing interest and creating alliances...

Growing Interest and Creating Alliances

1. Using a wide variety of media and person to person contact to disseminate information and raise awareness of the JHS.

2. Sponsoring a weekly radio show which airs at dinner time perhaps on Jackson State University’s radio station, **JHS Family Tales at the Table**. For each show, a community leader might be invited to read a compelling African-American story that gathers family into conversation. Perhaps the Jackson State University literature department could develop this program. Before the story is presented, a brief celebration of the accomplishments of JHS members could be given. Community leaders could be self or other nominated and selected by the radio station to represent children, adults and elders who are esteemed by their communities. After the story is done, questions could follow, perhaps one or two that would spark thinking.
3. Having 3-5 minute radio spots--**Living Long and Well**--to present research findings, feature highlights from participants in the study and what it means to them, or emphasize the Speaker’s Bureau. Perhaps Jackson State University communication arts program students could produce these as part of their course work.

4. Having a regularly scheduled “chat room” on the JHS Web site to entertain issues and concerns identified by the community.

5. Could a newspaper story be done (with permission) periodically on the family/ies with the highest number of members in the study as a way of celebrating this family’s contribution to the study and understanding how heart disease affects all families?

6. Disseminating first-hand information in places where the community regularly gathers (especially churches--“the seat of the Black community”) with a **Speaker’s Bureau** of ARIC participants and other well-informed community members to “dispel myths” and engage conversation.

7. Disseminating the community-driven motto which was generated from this study for the JHS: **A Legacy of Health**, throughout the community in written and verbal communication. Other possibilities from a community-driven perspective might include:

   - **Holding a contest within the schools, elementary, secondary and colleges, to develop a community logo to join with the official multi-institutional logo which has already been developed for the JHS.**

   - **Establishing a Print and Media committee with membership including artists as well as community members with varying presentational skills to work with the JHS Health Education Specialist in creating print and media presentations which address community concerns as they describe the JHS and its historic gift.**

8. Participating businesses could be recognized as **Friends of the Jackson Heart Study.** Much as local businesses create partnerships with local schools to support education, the JHS and businesses could work together as partners in creating a legacy of health for the Jackson community. Possibilities might include...
Hosting forums on the JHS within various businesses to generate co-participation during the planning and implementation of the study; developing educational programs targeted for that business to assure that all employees become participants in the JHS, not just those who receive time away to attend examination visits.

- Providing “brag boards” located at BOTH the JHS clinic and partnering businesses to acknowledge contributions of employee time to the study.
- Articles in the local papers and JHS newsletters about persons within these partnering businesses; etc.

9. Providing health care providers with links to patient educational programs and placing heart health fact sheets in their offices to provide beneficial information for their entire patient population.

10. Placing display racks about the JHS and its offerings in health care provider offices.

### B. A community-driven model to inform building paths to participation...

<table>
<thead>
<tr>
<th>Paths to Participation: A Study from the Heart: Jackson Heart to Heart</th>
<th>1. Building on the notion of story telling, offer co-involved training forums, a <strong>Jackson Heart to Heart</strong>, to offer heart-to-heart learning for each other assure that everyone who wants can benefit from the JHS. Such community-driven capacity building would also develop spokespersons for the JHS throughout the populace. Viewed as connecting conversations among study examinees, researchers and the larger Jackson community, these regular community-driven learning forums would share culture-specific stories of early prevention, risk factors, ways to know your own risk, how to know something is amiss, and what to do when you recognize concerns. These Jackson Heart to Heart sessions might focus on topics of common concern to the entire biracial community as a say of building new contacts and associations across ethnicity.</th>
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<td></td>
<td>2. Sponsoring <strong>Jackson Heart Storytelling Hours</strong>-- as the “next step” in the JHS. These would be regular forums where Black and White, researchers and participants, community friends, come together to “just hear people talk, hear people talk and record it. Let them express themselves and what has happened to them across the years...”</td>
</tr>
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</table>
3. Co-sponsoring a **Heart Health Resource Kiosk** that could be permanently located at the Jackson Medical Mall and might periodically go “on the road” to other community forums in order to provide a centralized place for health information to the community? Such a kiosk could provide hands-on training for persons taking part in the Heart to Heart lay health training sessions as well as opportunities for partnering with other health organizations to disseminate culture-specific information.

4. Sponsoring a regular series of 4 well designed and informational **Living Long and Well** sessions led by JHS researchers, followed by break out sessions facilitated by students from the three participating academic institutions with a reception to follow? Participants in these sessions might receive certificates at the end of the sessions which recognize their achievement in completing the “course.”

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<tr>
<th>Paths to Participation: Creating and Celebrating Community: JHS Community Heart Scholarships</th>
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<tr>
<td>5. Could a <strong>Community Heart Scholarship Fund</strong> be established and a donation made for every visit of every participant? Say $10 per visit per participant? For example, could we ask White and Black supporters to contribute the small sum in recognition for each completed participant visit? This might call in schools and community centers, as well as business who might support the fund, to also participate in recruiting and retaining participants. Each year proposals for community scholarships (perhaps $1000 limit) could be reviewed by a <strong>JHS Council of Peers</strong>. This group of community leaders could be advisory to the research team. Including African-American students in recruiting and retaining participants might also encourage them to apply for educational scholarships through the JHS Community Heart Scholars fund.</td>
</tr>
<tr>
<td>6. Hosting a parade and gathering the JHS “Family and Friends” on Juneteenth Day each year in the parking lot of the Jackson Medical Mall. This could be an occasion for persons in the cohort to share first-hand experiences and for the entire community to hear the major findings as they emerge. The first such gathering might be the kick-off for the study in July, 2000.</td>
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<tr>
<td>7. Hosting a Kwanzaa or other spiritual event to celebrate and offer thanks for the gifts of friends and family to each other in participating and supporting the ongoing gift of the JHS.</td>
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</table>
These or other community-wide celebrations could be the forum for awarding the Community Hearts Scholarships, recognizing the family with the most participants, recognizing accomplishments of the entire community--researchers and participants, and including the “extended family” of NHLBI to report on study findings to date.

<table>
<thead>
<tr>
<th>Paths to Participation: The Friendship Tree</th>
<th>8. Could a local foundation be tapped to support health care, home utilities, economic and social services, joining together with the JHS family to create virtual resource directory for accessing a wide range of necessary services and programs?</th>
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<tr>
<td></td>
<td>9. Can the JHS connect with and mutually support other community groups, such as Police Department Neighborhood Watch Programs, community scouting programs, and others to promote and support issues of concern to the entire community; for example Jackson Heart speaks WITH the neighborhood on violence?</td>
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<td>10. Friends of the JHS Volunteers to:</td>
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<td>➢ serve as “community ombudspersons” during clinic visits, in follow up calls to assure that all went well, assisting with mailings or other community-focused activities.</td>
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<td>➢ be available to help persons who are not able to read the consent forms to read it with them.</td>
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<td>➢ provide volunteer child care for cohort members while they complete their visits.</td>
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<td></td>
<td>➢ staff a “community hotline” phone to field and direct questions concerning the study or community needs the JHS might be able to respond to.</td>
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</table>
## III. As an Infrastructure Toward Community, Participants and Researchers as Co-investigators using...

### A. A community-driven model to inform culturally appropriate protocols and consent...

| Interpreting Concerns: Culturally Appropriate Research Protocols | 1. Including culturally appropriate language which must come from continuing conversations between JHS investigators and the community to improve recruitment, retention, data quality and completeness.  
2. Developing formal mechanisms for community members to collaborate in the development and ongoing management of study protocols.  
3. Gaining input from the community through community protocol committees which could help the JHS investigators to look for and maintain the “comfort zone” for questions and answers between study participants and staff. |
|---|---|
| Interpreting Concerns: Informed Consent | 4. Creating with the community a video tape or a photo novello consent which might help improve understanding of the JHS by study participants leading to higher levels of comfort with participation.  
5. Including language developed by community members and JHS investigators in consent material which could help improve understanding of the consent process. |
| Interpreting Concerns: Informed Consent for Genetic Studies | 6. Assuring community involvement in decisions about uses of genetic material. This could be accomplished by means of a Genetic Data Oversight Committee either as a stand alone or part of a broader community oversight board for the study. This would be in addition to the already initiated inclusion of community membership on the JHS Publications Committee.  
7. Conducting community forums to discuss and, hopefully, improve understanding of genetic research. |

### B. A community-driven model to inform the conduct of the study...

| Gathering the JHS Family: Participants | 1. Reconfiguring the Steering Committee to include voting community members; |
| and Community as Co-investigators | 2. Assuring community contributions to this report beyond that of the already collected stories;  
| | 3. Including community members as co-authors on papers which report findings;  
| | 4. Holding open NHLBI site visits announced to the community and scheduled in locales to accommodate community attendance;  
| | 5. Co-writing the Manual of Operations and Training Manuals for participant recruitment as well as examinations and interviews.  
| | 6. Featuring a researcher from each institution quarterly in the JHS newsletter.  
| | 7. Continuing the successful JHS monthly Heart Healthy Luncheon series which brings the community together for informal gathering and celebrates the life experiences of its members.  
| | 8. Creating opportunities to co-participate in cross-cultural encounters to uncover meanings that reflect common and shared interests.  
| | 9. Creating an organizational structure for the work of the study that recognizes and respects participation across institutions as well as with the community as co-investigators.  
| | 10. Rotating informal sessions for each of the centers to call together the research team to brainstorm together on thought-provoking issues and ideas relevant to the study. The JHS Scientific Seminar Series is one vehicle, others such as the Community Mobilization Seminar Series might be considered which address a variety of aspects.  
| | 11. Recognizing communal participation taking every opportunity to express gratitude for participation, provide appreciative mementoes and incentives over the course of the study, not just as a one-time thing.  
| | 12. Sharing in meals and other community activities to nurture connections.  
| | 13. Engaging in ongoing inter-cultural dialogues among Blacks and Whites, researchers, researched and the community.  
| Gathering the JHS Family: Knowing and Connecting | }
Appendix 3.3  Recognition of Participation in HII and AFU Interviews
Appendix 3.4  Participant Recognition of Cohort Numbering
APPENDIX 4 INSTRUCTIONS FOR COMPLETING PAPER FORMS
Appendix 4.1 Instructions For Completing Paper Forms General

1. Background

The Jackson Heart (JHS) Study utilizes computer-assisted direct data entry as its primary mode of data collection. Nevertheless, the existence of paper forms is necessary for situations in which direct data entry is not possible. In such instances, data is collected on paper forms and then entered on the computer at some later time. The purpose of this document is to provide instructions for completing these paper forms. It should be read carefully prior to working with any forms. Specific sets of instructions associated with each form (QxQs) should then be read for those forms that are of interest.

2. Form Structure

Most of the paper forms in JHS are designed to correspond exactly to the computer screens used for data entry. However, the quantity of text showing on one paper page will not usually match the quantity of text on a screen. For example, the first page of a form may show items 1 to 10, while the first screen of the form may show items 1 to 8.

Most forms are structured as follows:

First page:
- a. Form Title
- b. "Header" Information
  1. Participant's ID Number
  2. Contact Year
  3. Form Code (preassigned 3-letter code)
  4. Version (1-letter code and date)
  5. Participant's Last Name and Initials
- c. Summarized Instructions
- d. First Screen of the Form

Following pages:
- a. Form Title, Code, and Version
- b. Successive Screens

3. General Instructions for Completing and Correcting Items on the Forms

All items fall into two main categories: (1) fill in the boxes, and (2) multiple choice. Techniques for completing each of these types of items, as well as making corrections, are described below. A general rule is to record information only in the spaces provided (except for some error corrections).

3.1 Fill In The Boxes: Recording Information

When alphabetic information is required, print the response beginning in the leftmost box using capital letters. Punctuation may be included.

Example: If the participant's last name were O'Reilly, it should be entered as follows:

```
LAST NAME: O' R E I L L Y
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If the response contains more characters than there are boxes, beginning with the first character enter as many characters as there are boxes.
Example: If the subject's last name were Hobgoodnotting, it should be entered as follows:

LAST NAME: H O B G O O D N C T T I

Whenever numerical responses are required, enter the number so that the last digit appears in the rightmost box. Enter leading zeroes where necessary to fill all boxes. (This does not apply to the address section or to any item which combines alphabetic and numeric information. Such items should be treated as alphabetic.)

Example: If the participant's diastolic blood pressure was 96, it should be coded as:

Diastolic: 0 9 6

In some cases, numeric fields have a pre-printed number of decimal places. Also, it is possible that the QxQ instructions will specify the number of decimal places to be recorded. Instructions on how to round values to the expected number of decimal places are found in the QxQ instructions. When necessary, enter trailing zeros to fill the requested number of places to the right of the decimal point. Leading zeros may be needed so that all boxes to the left of the decimal are also filled.

Example with trailing zero: If the participant takes twelve vitamins per day, it should be recorded as:

Number per day: 1 2 0

Example with leading zero: If the participant takes two and one-half vitamins per day, it should be recorded as:

Number per day: 0 2 . 5

In most cases when dates are recorded, slashes ("/") are used as the separator characters for month, day, and year. These are usually pre-printed in the response field. The format to be used to record dates is indicated under the boxes. If not, the QxQ instructions will indicate which format and separator to use. JHS uses the U.S. order for recording dates (month/day/year). The QxQ instructions may also contain information on how to handle partial dates. When necessary, use leading zeros within each date unit (month or day or year) so that each box is filled.

Example: Data collected on April 3, 2000 would be recorded as:

Date of data collection: 0 4 0 3 0 0

m  m  d  d  y  y

JHS usually records time using a 12-hour clock, with AM or PM indicated separately. In most cases, colons (":") are used as the separator character for hours and minutes, and are typically pre-printed in the response field. The format to be used is indicated under the boxes. If not, the QxQ instructions will indicate which format and separator to use. When necessary, use leading zeros within each time unit.
(hour or minute) so that each box is filled. Note that midnight is recorded as 12:00 AM, and noon is recorded as 12:00 PM.

Example: A time of fasting determination of 8:05 in the morning is recorded as:

a. Time of fasting determination:  
   0 8 : 0 5 
   h h m m

b. AM.................A
   PM.................P
3.2 Fill In The Boxes: Correcting Mistakes

If a number or letter is entered incorrectly, mark through the incorrect entry with an "X". Code the correct entry clearly above the original incorrect entry.

Example: If the participant's systolic blood pressure was actually 130, but was incorrectly entered:

Systolic: 1 3 9

The correction would look like:

Systolic: 1 3 9

If a mistake is made, corrected, and then it is discovered that the correction is incorrect, make a second correction as shown below:

Systolic: 1 3 9

3.3 Fill In The Boxes: Unknown Or Inapplicable Information

If an item of this type (either alphabetic or numeric) does not apply to the subject being interviewed, leave it blank. For example, if the participant does not have an "other" phone number, that item is left blank. Similarly, if the form provides spaces for three measurements, but only two are taken, the third space is left blank.

If the item does apply, but the response is unknown, mark through the box(es) with two horizontal lines.

Example: The question "How old were you when you had your first heart attack?" is asked, but the participant does not recall how old s/he was. The question does apply because it has been established that the participant has had a heart attack, but the answer to this question is not known. In this case, the response would look like:

How old were you when you had your first heart attack?
4. Multiple Choice: Recording Information

In this type of question several alternatives are given for the answer, each having a corresponding letter. When it is decided which alternative is most appropriate, circle the corresponding letter in the space provided. Always circle one letter only.

Example: If the participant indicates that they have never had chest pain or discomfort, the response would look like:

Have you ever had any pain or discomfort in your chest?  
Yes  Y  
No   N

5. Multiple Choice: Correcting Mistakes

If a response is coded incorrectly, mark through the incorrectly coded response with an “X” and circle the correct response.

Example 1: The actual response is No, but Y was circled incorrectly. The correction looks like:

Yes  Y  
No   N

Example 2: If a mistake is made, corrected, and then it is discovered that the correction is incorrect, make a second correction as shown below:

Yes  Y  
No   N

6. Completing "Header" Information

The following guidelines should be observed in filling out the "header" information located at the top of the first page on all forms:

ID NUMBER: Write in the participant's 7-digit ID. The first box contains the letter J, followed by the 6-digit numeric portion of the ID number.

Example: ID NUMBER: J 9 9 9 9 9 9

CONTACT YEAR: Fill in the appropriate contact year for the form. Use leading zeroes. Note: This item may be pre-coded on some forms.

LAST NAME: Code the response beginning in the leftmost box using capital letters. If the name contains more letters than there are boxes, beginning with the first letter enter as many letters as there are boxes. Punctuation (e.g., apostrophes and hyphens) and blanks may be entered as part of the last name. Follow the guidelines and examples given above for alphabetic "fill in the boxes" items.

INITIALS: Record the participant's first initial in the first box and middle initial in the second box. If a female participant is married and uses a "maiden" name (father's surname) as a middle name, use that
initial as the second initial. Otherwise, if the participant has more than one middle name, record only the first initial and the second initial. If there is no middle name, record the first initial in the first box and leave the second box blank.

Example 1: A participant's first initial is K, but he has no middle name. The entry would be as follows:

INITIALS: K

Example 2: If the participant's full name is John Oscar Van Camp, Jr., and the participant specifies that his last name is "Van Camp", it should be entered as:

LAST NAME: VAN CAMP
INITIALS: J O

7. Skip Patterns ("Go to" Boxes)

Skip patterns occur in many multiple choice type items. Here, if a certain response is selected, it is necessary to skip over one or more items to the next applicable item. This is indicated by an arrow from the response which necessitates a skip to a box containing a "go to" statement. If that response is selected, the next item to be asked is the one indicated in the box. If the other response is selected, always proceed to the next item unless otherwise directed. The box will also indicate the screen containing the "go to" item if that item is not on the current screen.

Example: 7. Since we last contacted you, have you had any pain or discomfort in your chest?

Yes Y
No N  Go to Item 20, Screen 5

In this case, if the response is "No", skip to Item 20 on screen 5. If the response is "Yes", proceed to the next question, Item 8.

Occasionally, a skip pattern will occur in a fill-in type item. In those instances, specific instructions are provided on the form. Again, if the skip criteria are not satisfied, continue with the next item.

A few items will trigger a skip regardless of the response. For these, follow the instructions on the form.
Appendix 4.2  General Instructions: Completing Computer Data entry Screen

SEE MANUAL 11, DATA MANAGEMENT
Appendix 4.3 Instructions for Recording Responses that Do Not Match Precoded Response Categories

Most of the questions in the JHS instruments have precoded responses. There are a few questions, however, that are open-ended that is, you must write in a response to the question. Some questions have precoded responses as well as an “Other (SPECIFY)” category. If the respondent’s answer does not fit into a precoded answer, you must specify the response. The recording practices below must be followed at all times to assure that the response recorded accurately reflects the respondent’s answers and to assure that questionnaire data can be converted to machine-readable form.

- You must listen to what the respondent says and record the appropriate answer if the response satisfies the objective of the question.

- In recording answers to open-ended questions or “Other (SPECIFY)” categories, print the response verbatim.

- Record the response immediately after it is given.

- Use a black ball point pen provided by the Exam Center.

- Record in the white space below the questions any responses that “don’t quite fit” in one of the response categories. Your notes will help the analysts in understanding points of confusion, difficulty, etc.

- Print or write legibly.

- If a respondent refused to answer a question, write “refused” in the left margin beside the question.

- A single answer choice code must be circled in each question to represent the respondent’s answer. The only deviation from this rule is for disease questions which are subdivided into several diseases and an answer code is to be circled for each disease listed.
APPENDIX 5  INTERVIEWER TECHNIQUES
Appendix 5.1 Overview of Interviewing

A. Interviewer bias – includes anything that creates a systematic difference between responses obtained by different interviewers

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

B. Characteristics of a good interview

3. There is an appropriate atmosphere
   - friendly, but businesslike
4. The respondent is at ease
   - female interviewers may be perceived as less threatening
   - ensure confidentiality of participant
   - someone much older than respondent may be viewed as more judgmental
   - space for interviewing is appropriate, quiet, friendly
5. The interviewer obtains the answer to the question that is asked
   - proper use of probes
   - repeats question, rather than interpreting it
6. Clarification is obtained for confusing answers
7. The interviewer gives only neutral responses to the respondent's answers
8. The response is recorded accurately

C. Specific skills required for interviewers

1. Be able to ask questions at the correct pace and in a conversational tone
2. Know the questions and response categories well enough to keep the interview flowing smoothly
3. Know when there are probes that can be used, and know how to use them
4. Be able to think as an interviewer, and put aside other roles (researcher, and health care provider, etc.) for the time being
5. Be able to maintain a positive attitude about the interview so that respondent feels that the interview is important
6. Be able to keep some level of control over the interview process, e.g. by rewarding the respondent for answering questions, and not for other behavior
7. Neat, pleasant, professional dress; not too timid, not too aggressive
Appendix 5.2 Administration Of Interviewing

B. Administration of work

1. Supervisor
   a. One supervisor for each ten interviewers
   b. Importance of prompt review of work, and quick feedback
   c. Face-to-face conference with each interviewer once a week

2. Other considerations
   a. Good pay and working conditions help keep up morale

3. Tracking procedures
   a. Response rate, overall and by interviewer
   b. Reasons for non-response
   c. Length of interview, overall and by interviewer

B. Interviewer training

1. Must cover all aspects of the interview
   a. Introducing yourself
   b. Handling people who are reluctant
   c. Following instructions for administration of interview form
   d. Obtaining consent
   e. Answering consent
   f. Obtaining privacy for the interview
   g. Setting respondent at ease
   h. Administering the interview
   i. Ending the interview
   j. Importance of role playing, using both standard and problematic situations
   k. Discuss problems that arose
C. Quality control of field work

1. Observation
   a. Supervisor going with interviewer
   b. Tape recording
   c. Monitoring telephone interview

2. Editing
   a. Field editing
   b. Editing by supervisor — edit first few interviews, if no problems then only need edit a sample of remaining interviews

3. Validation
   a. That interview was done — by re-interview, telephone call, or sending a letter

D. Ways to reduce the standard errors from interview effects by 10% for at least the one-third of items most affected by interviewers (Source: Fowler FJ, Mangione TW)

1. Increase effective sample size by about 20% (if simple random sample)
2. If interviewers receive less than 1 day of basic training, increase by a day or two
3. Tape all or a sample of interviews; review one a week per interviewer, provide feedback
4. Rewrite questions to reduce the need for probing and make administration and reading of questions easier
5. Reduce the number of interviews per interviewer by 20% by using 20% more interviewers

Reference

Appendix 5.3  Jackson Heart Study Interviewer Techniques

1. Standardized Interviewing Techniques

The Jackson Heart Study is a single site study being conducted in the Jackson Mississippi area, with African-American persons aged 35-84. The aim is to produce a study that represents 6,500 people throughout the Jackson area in Madison, Rankin and Hinds counties.

In order to produce valid and reliable data, the study designers must pay attention to the training and the methods in which the data are collected. Thus, a standardized approach to interviewing and the training of interviewers is necessary. The study is standardized through the use of scripts in training, centralized training of supervisors, setting of qualifications for supervisors, reviewing of data that is collected, listening to tapes that are produced at interviews, and finally observing the interviewer in the field.

Scripts are used to teach you techniques in probing as well to determine how well you are following skip patterns in the forms and adhering to the various aspects of protocol. Scripts are specifically used in the Rose Questionnaire. All of your interviews will be taped and you will gain knowledge about how to do this talking with experienced interviewers who are systematically reviewed by your supervisor to determine that you are asking the questions as written and are not leading the study respondent or providing answers for them. You will occasionally be observed through monitoring visits.

The study is further standardized in centralizing training for supervisors and where possible for the interviewers. The study initially will train local interviewer supervisors who will be responsible for training on site as the need for new personnel is required.

2. Dealing with the Sample Population

The sample members for Jackson Heart Study will include a variety of persons who, generally, will have characteristics similar to those encountered with any household survey. Some of the situations you may encounter at the household, along with suggestions for dealing with them appropriately, follow:

1. Fear of Being Victimized – Some of your respondents may refuse to participate in a survey because they are afraid of being victimized in some way. It is your responsibility to assure the sample member of the legitimacy of your call/visit and intentions and to make the respondent feel secure. Your identification badge and letter will aid you in reassuring the respondent.

2. Handicaps – If a sample member seems to have a handicap that will interfere with proper completion of the interview, would cause undue stress for the sample member, or prevent the sample member from completing the clinic/examination, do not attempt to complete the interview with her/him. Determine if there is a person available who is knowledgeable about the sample member’s health and tactfully obtain information which will help determine if the sample member should be excluded from the study. If such a person does not exist, thank the sample member for his/her time and terminate the interview. Code the result appropriately and provide explanatory notes so that your supervisor can evaluate the case.

3. Difficulty Understanding Questions – Some of your respondents may have difficulty in comprehending the questions slowly and allow the respondent adequate time to respond. Repeat the question, if necessary. (Unless specifically allowed by the specifications, do not define and explain, which may result in obtaining a biased response.)

4. Tendency to Stray from the Topic – Some respondents will welcome the opportunity to talk with someone who is neutral about their health problems. Attempts to explain their problems or vent
their feelings may cause them to stray from the questions being asked. You must be careful to control the interview situation, while not alienating the respondent.

5. Tendency to Respond in a Socially Desirable Manner – Some of the respondents will rely on you to help with a response or offer responses that they think are what you or the government would like to hear rather than expressing their knowledge or opinion about a given subject. Keep in mind that we are trying to gather objective data on the sample members’ health. Reassure sample members that there are no right or wrong answers to the questions and encourage them to respond according to their experience and knowledge.

3. Interviewing Guidelines

The survey response rate and the quality of the data collected depend on how well you handle various interview situations. Every interview situation will be different, and it is impossible to enumerate every possible situation that you might encounter and suggest ways for handling those situations. There are, however, some basic guidelines presented in this section that, if followed, will assist in obtaining a sample member’s participation in the survey and obtain accurate data.

4. Contacting the Respondent

- **Official Notification:** Jackson Heart Study staff will have notified appropriate law enforcement personnel, post offices and community leaders of the study. If interviewer/recruiters are questioned in the field, show their ID badge (which should always be worn in the field) and other identifying information.

- **Leaving Messages:** Interviewer/recruiters will leave door hangers along with business cards. This will provide an opportunity for someone in the household to directly contact the Interviewer/recruiter or Jackson Heart Study center staff to schedule an appointment.

- **Interviewing People You Know:** Interviewer/recruiters are not allowed to conduct interviews with friends, relatives or acquaintances. If the Interviewer/recruiter discovers that the respondent is someone s/he knows, inform her/him of the Jackson Heart Study policy and record on HEF form. Jackson Heart Study wants to be able to ensure confidentiality to all respondents and to maintain a professional relationship in the interview setting.

- **Your Introduction:** Initial contacts with sample members will be made in person (or by the printed Jackson Heart Study door hanger). When you meet with a sample member, read the introduction as it is printed. The focus of the introduction is to identify the Interviewer/recruiter, the organization you represent and the purpose of your visit. Attitude: Approach each respondent with a positive, self-assured and matter-of-fact manner. Friendliness, not familiarity, is an asset.

5. Obtaining Participation

You will be provided with the following materials to motivate sample members to participate in the study:

- Introductory letter,

- Study brochure, and

- Copies of local newspaper clippings and endorsements.

You may, however, encounter questions about the survey or objections to participation. A list of possible questions and suggested answers appear below.
6. Commonly Asked Questions

A. “Will I have to take any drugs and/or medications?” Explain to the respondent that there will be no drugs or medication administered during the clinic visit -- only related tests, such as EKG, Lab test, Physical Examination.

B. “How often and how long are the clinic visits?” Explain clinic visits are (1) once every three years, (2) clinic visit will last approx. 2-4 hours.

C. “What type of tests will be administered?” Name all tests that will be administered.

D. “Will transportation be provided?” Transportation will be provided as needed.

E. “Are child accommodations provided?” Yes.

F. “How do I know you and the survey are legitimate?” Repeat your introduction and give the respondent the introductory letter and brochure. Suggest that the respondent call the number on the brochure for information and verification. Also point out that the local health officials are aware of the survey and show the sample member local newspaper clippings and endorsements. Above all else, always wear your picture ID badge in the field and have it visible.

G. “What’s this survey about?” Explain that we are interviewing approximately 6,500 randomly selected people ages (35-84) in 3 counties in the state of Mississippi, Hinds, Madison and Rankin, to collect data about their health. The data collected will help the National Institutes of Health, and local area health professionals to understand better, the factors associated with heart disease.

H. “I don’t want to buy anything!” “We are not selling anything. We are doing an important research study for the National Heart, Lung and Blood Institute.”

I. “Why interview me?” “Researchers used scientific sampling procedures to select a random sample of the people in your community. It is important that you participate because we can’t replace you with someone else if you don’t.”

J. “Who’s paying for this study?” The National Heart, Lung and Blood Institute is sponsoring the study.

K. “I’m too busy” “Then let’s make an appointment for some other time that is more convenient for you. We can make the appointment now.” Note: If the participant does not make an appointment then and request for you to call back, tell them you can call back tomorrow morning, afternoon, or evening. “Which would you prefer?”

L. “My answers won’t be of any help.” Explain that there are no right or wrong answers and their opinions and experiences will be helpful to the study.

M. “I don’t want everybody to know my personal information.” Advise that “Your answers will be kept fully confidential. The information that you give us will be analyzed statistically, and there will be no way that your name will be connected with your answers. Your name, address, and phone number will be separated from your answers, and all identifying information will be destroyed when the study results are reported. Your answers will not be given to your doctor or anyone else responsible for your health care without your permission and will not, in any way, affect the care you receive from them.”
N. “I can’t help you because I never had heart problems.” Explain that you still need to talk to them about their health and that the study is based on selecting people from the general population, most of whom will not have heart problems. Also, explain that if a question is asked for which they don’t know the answer, they can simply say “don’t know” and you will move on to the next applicable question.

O. “Will this affect my medical care?” Assure the sample member that participation in this study will not affect any medical care s/he now receives or might receive in the future. Also, explain that participation in the survey is voluntary and that all data collected will be kept fully confidential.

P. “My doctor may not want me to be in the study.” Inform the sample member that area physicians are in support of the Jackson Heart Study and show her/him copies of local endorsements. Suggest that the sample member complete the home interview, and if s/he still feels uncomfortable about the clinic examination, s/he may contact his/her physician to discuss the study.

Q. “What do I get out of the study?” “There are several things that you will get from the study. You will receive free of charge a state-of-the-art medical examination that would cost about $1,200 if it were not part of the program. You may find out that you have a medical condition you have been unaware of and you will be able to get treatment from your personal physician for it earlier. You will also have an opportunity to participate in one of the most important health studies ever conducted. Legacy of Health.”

R. “How long will this take?” The questionnaire today will take about 30-40 minutes, depending on your answers. Let me start and I’ll move through the interview as quickly as I can” (Immediately ask the first question).

S. Request for information that you are unable to provide. If you are unable to answer a sample member’s question about the study, advise her/him that you will talk to your supervisor to get the needed information, and that you will be back in touch in a day or so. Then talk to your supervisor as soon as possible.

T. “What will the clinic visit involve?” If this question is asked during enumeration, provide the respondent with a brief explanation, such as: “The clinic visit will involve a physical examination by highly trained clinic staff using modern equipment and an interview.” If this question is asked later during the visit, interviewer/recruiters will review the Jackson Heart Study brochure with the respondent. The Jackson Heart Study brochure will consist of the clinic scheduled activities and a brief description of the major tests that will be conducted at the clinic.

U. “Will I get results of my test?” “Any abnormal findings will be made known to you, as well as either complete results or a summary of results of important tests. For example, we will provide the actual blood pressure values, blood cholesterol and fasting blood sugar results, and many more. Your lab results will be given to your primary physician also.”

V. “Where did you get my name or why have you come to my house.” Your name came from the driver’s license list for Mississippi.

W. “I would like to participate but I can’t take that much time off work.” Tell the respondent that the Jackson Heart Study project has received extensive community support and that Jackson Heart Study staff will be happy to send a letter to the employer requesting time off (see attached letter). Be sure to note that the respondent has requested this letter and inform your supervisor as soon as possible.
X. “I heard you can get AIDS from blood tests.” Explain that the clinic uses only sealed, disposable needles to draw blood. The needles will not be “shared”; therefore there is not a known risk for AIDS from blood drawing.

Y. “I don't like the idea of blood tests.” “I don't like to have my blood drawn. The clinic staff is very well trained and draws blood with a minimum of discomfort. The blood tests are one of the most important parts of the Jackson Heart Study and are needed to compare with your other study results.”

NOTE: If the respondent refused to have blood drawn, consider that a refusal for the clinic appointment. Try, however, to obtain a home interview without scheduling the appointment.

Z. “I just told you the answer to that question.” “I'm sorry I repeated the question. I don't want to rely on my memory to record your information correctly.” Note that this can be avoided if you realize the respondent has answered the question by a lead-in such as “I know this sounds repetitive but could you tell me...” or “You may have told me this before but just to make sure I have it right...”

The important point to remember when answering questions or overcoming objections is to try not to alienate the respondent. If you feel that you are unsuccessful in countering the respondent’s objections, politely thank her/him for his/her time and terminate the interview. Try to “leave the door open” for someone else to talk to the sample member and encourage her/him to participate.

7. Conducting the Interview

The interviewer must help the respondent to feel at ease and comfortable with the interview. During the initial contact and throughout the interview, you should:

- Maintain a positive attitude.
- Repeat that any information the respondent gives you will be kept confidential if s/he appears to be apprehensive about providing information,
- Maintain control of the interview.
- Assume a nonjudgmental, noncommittal, neutral approach to the respondent and the subject matter, so that the sample member will feel comfortable answering the questions truthfully.

The process of asking the questions, probing, and recording responses correctly is crucial to obtaining usable, high-quality data. The standard practices listed below must be followed.

8. Asking the Questions

- Ask the questions using the exact words printed in the questionnaire.
- Ask the questions in the exact sequence in which they appear or as instructed. Whenever you are not to ask questions in sequence, a skip instruction will appear beside the response categories for the question asked. (Skip routing instructions are discussed in more detail later in this chapter.)
- Ask every question specified even when a respondent has seemingly provided the answer to the question when another question was asked. The answer received in the context of one question may not be the same answer that will be received when the other question is asked.
• If the answer to a question indicates that the respondent did not understand the intent of the question, repeat the question.

• Read the questions at a moderate speed, preferably at a pace of about two words per second.

• Avoid suggesting answers to the respondent. As noted elsewhere in this manual, the sample members may rely on you to help with an answer to a question. Your job as an interviewer is to ask the questions, make sure the respondent understands the questions, and then record his/her responses. Do not assist the respondent in selecting responses.

• Read transition statements just as they are printed in the questionnaire. Transition statements are designed to inform the respondent of the nature of a question or a series of questions, to define a word, or to describe what is being asked for in the question.

• Sensitive questions should be asked in a neutral manner, which should not differ from the normal professional flow of the interview. The respondent may be more comfortable if you avoid eye contact when asking sensitive questions.

• Read questions in a natural tone, following the punctuation in the question. Only emphasize words that are underlined or appear in bold. When response categories are to be read, put a brief pause between the options so the participant knows what the choices are.

• Do not show the questionnaire to the respondent. You do not want the respondent to see the questions and response categories of the questionnaire. For this reason, you will want to arrange the seating so that you are sitting across from the respondent. When it is appropriate for the respondent to see the response categories to a question, the questionnaire will instruct you to guide the respondent to look at a designated RESPONSE CARD.

9. Probing

You will be required at times to probe to obtain a more complete or more specific answer from a respondent. Chapters 3 and 4 provide explanation of the questions you will ask. When you know the objective of a question, you will be able to judge whether a response is adequate or inadequate. In order to elicit complete, adequate answers, you often will need to use an appropriate neutral or non-directive probe. The important thing to remember when probing is that you must not suggest answers or lead the respondent. General rules for probing follow.

• Use neutral questions or statements to encourage a respondent to elaborate on an inadequate response. Examples of neutral probes are “What do you mean?”, “How do you mean?” “Tell me what you have in mind.” “Tell me more about…”.

• The silent probe, which is pausing or hesitating to indicate to the respondent that you need more or better information, is a good probe to use after you have determined the respondent’s response pattern.

• Clarification probes should be used when the response is unclear, ambiguous or contradictory. Be careful not to appear to challenge the respondent when clarifying a statement and always use a neutral probe.

• Repeat the question if the respondent misunderstood or misinterpreted the question. After hearing the question the second time, the respondent will likely understand what information is expected.
• Unless you have been provided with a response code of “Don’t know”, the “I don’t know” response almost always requires a probe since this response can mean one of several things:
  - The respondent doesn’t understand the question and says “Don’t know” to avoid saying s/he doesn’t understand;
  - The respondent is thinking the question over and says “Don’t know” to fill the silence and gain time to think;
  - The respondent may be trying to evade the issue because s/he feels uninformed, is afraid of giving a wrong answer or the question seems too personal; or, the respondent may really not know.

Some of the questions in the Jackson Heart Study ask about recall of events over time. You may assist the respondent without violating probing rules by working with her/him on math or pinpointing dates or events (such as age a parent was diagnosed with a specific disease). Another way to help pinpoint more accurate information is to ask respondent to think about time of year or season when an event occurred.

10. Recording Responses

Most of the questions in the Jackson Heart Study instruments have precoded responses. There are a few questions, however, that are open-ended – that is, you must write in a response to the question. Some questions have pre-coded responses as well as an “Other (Specify)” category. If the respondent’s answer does not fit into a pre-coded answer, you must specify the response. The recording practices below must be followed at all times to assure that the response recorded accurately reflects the respondents’ answers and to assure that questionnaire data can be converted to machine-readable form. Detailed Instructions for Completing Paper Forms may be found in Appendix 10.

11. Instrument Conventions

Certain conventions are used consistently in the Jackson Heart Study instruments. Familiarity with these conventions will help you use the instruments with ease and confidence.

12. Instructions to the Interviewer

Your instructions are always in CAPITAL LETTERS, and they are not to be read to the respondent. Often, your instructions are also in brackets. For example:

37. Have you ever smoked a pipe regularly?
   [CODE “NO” IF LESS THAN 12 OZ. IN A LIFETIME] .................................................................Yes Y
   .............................................................................................................No N

   Go to Item 44

Instructions to interviewers may also appear in boxes. Boxed material in capital letters are interviewer instructions. Other statements which are in boxes but are not capitalized are to be read to the respondent. An example of each type of boxed statement appears below.
Did your natural father ever have or does he now have any of the following diseases? [READ EACH RESPONSE CATEGORY]

26a. Cancer? ......................................................... Yes 

Y

No 

N

Don’t know 

D

26b. Diabetes? (sugar in the blood) .......... Yes 

Y

No 

N

Don’t know 

D

26c. High blood pressure or hypertension (high blood)? .............. Yes 

Y

No 

N

Don’t know 

D

26d. Stroke? ......................................................... Yes 

Y

No 

N

Don’t know 

D

26e. Heart attack? ............................................. Yes 

Y

No 

N

Don’t know 

D
13. Questions

Questions are printed in upper and lower case type. Answer choices and codes are printed below the question. Answer choices are never read to the respondent unless they are included in the body of the question or unless you are instructed to do so. In Example 1 below, the answer choices are not read to the respondent; in Examples 2 and 3, they are read because they are included in the question or because you are instructed to do so.

**EXAMPLE 1**

14. What was the cause of your natural mother’s death? ……………………………………
   Cancer C
   Heart attack A
   Stroke S
   Unknown U
   Other (Specify) O

Specify: _________________________________________________________________

**EXAMPLE 2**

1. Compared to other people your age, would you say that your health is excellent, good, fair, or poor? …………………………………………. Excellent E
   Good G

If “No” or “Don’t Know”, Go to Item 28
EXAMPLE 3

36. (Do/did) you inhale the cigarette smoke?

[READ RESPONSE CATEGORIES]  Not at all  N
                           Slightly  S
                           Moderately  M
                           Deeply  D

14. Alternate Wording

Where you must choose the correct wording for a question, a choice of words or phrases is given in parentheses. The choice you make depends upon previous answers from that respondent. For example:

57. What (is/was) your (current/most recent) occupation? [IF MORE THAN ONE JOB,
RECORD OCCUPATION FOR JOB FOR
MOST HOURS WORKED PER WEEK.]

For currently employed respondents you would read “What is your current occupation?” For unemployed respondents, you would read, “What was your most recent occupation?”

15. Word Insertion

Many questions in the Jackson Heart Study survey instruments contain capitalized words or phrases within brackets. For these questions, you must insert the appropriate name, date, place, etc., as required by the questions. For example:

[IF YES TO ANY DISEASES IN QUESTION 26, ASK FOR EACH DISEASE.] How old was he
when he was first told he had [NAME OF DISEASE]? [ENTER “99” FOR “DON’T KNOW”; “98” FOR
AGES 98 AND OLDER.]

Age
27a. Cancer: 

27b. Diabetes: 

27c. High Blood Pressure: 

27d. Stroke: 

27e. Heart attack: 

53. How long have you lived in [NAME OF COMMUNITY]? ................................................................. YEARS

In the first example, you would insert the name of each disease specified in the preceding question. In the second example, you would read the name of your study community, e.g. Mississippi.

16. Skip Instructions

Skip instructions direct you to the next applicable question or item in the instrument. As with other interviewer instructions, they are in capital letters and appear with arrows, brackets, or as a lead-in to a specific question. Since skip instructions are crucial to the accurate administration of the questionnaire, see example below.
EXAMPLE 1

12. Have you ever taken birth control pills to prevent pregnancy? ………………………………………………………………………………Yes  Y
                                             Go to Item 17
                                             No  N

13. At what age did you start taking birth control pills for the first time? ………… age

14. Are you currently taking birth control pills? ……………………………Yes     Y  Go to Item 16
                                             No  N

15. At what age did you stop taking birth control pills? ………………………………… age

16. For how many years altogether have you used birth control pills? ……………… Years

C. HORMONE USE

17. Have you ever taken female hormone pills, skin patches, shots, or implants, including birth control pills for reasons other than preventing pregnancy? ……………………………………………………Yes  Y
                                            Go to Item 30
                                            No  N
                                            Don't Know  D
APPENDIX 6    DIET AND PHYSICAL ACTIVITY SUB-STUDY
Appendix 6.1  Diet and Physical Activity Sub-study Participant Information Brochure

(TO BE PROVIDED IN A FUTURE MANUALS UPDATE)
Appendix 6.2  Diet and Physical Activity Sub-study Informed Consent

JHS Logo  Informed Consent to Participate in the Diet and Physical Activity Sub-Study

Principal Investigators:
JHS Heart Study: Herman Taylor, M.D.
Diet and Physical Activity Sub-Study: Teresa Carithers, RD, MHS, LD
Patricia Dubbert, Ph.D.

You are being invited to take part in a more detailed study of dietary intake and physical activity, a sub-study that is part of the JHS. There are several questions that you may have before deciding to take part in this diet sub-study. This consent form will attempt to answer all or most of these questions. After reading this form and asking any other questions that you may have, you will be asked to sign the last page.

What is the Diet and Physical Activity Sub-Study of the JHS?

The diet part of the sub-study will help develop a diet survey instrument called a food frequency questionnaire, which accurately measures the dietary intake of African-Americans. The physical activity part of the study will help researchers learn about how physical activity is related to heart disease and other health problems.

Why was I selected to take part?

You were selected at random (like a flip of a coin) from all the persons taking part in JHS. If you agree to participate, you will be one of 500 persons selected.

What will I be asked to do and how much of my time will it take?

The diet part of the sub-study will require you to share information about your usual food and beverage consumption, and this will be recorded by an interviewer on a special survey form called a food frequency questionnaire. To be sure this questionnaire is measuring your food intake correctly it will need to be compared with a more specific measure of dietary intake over a 24-hour period. You will be asked to schedule four visits to measure intake over a 24-hour period and one additional visit to complete a final food frequency questionnaire. These visits will be scheduled over a six-month period.

All of the diet sub-study interviews will be arranged in the clinic of the JHS and will be scheduled to accommodate your personal needs as much as possible. Although three of these five visits can be scheduled on any day but Sunday, each participant is required to have one 24-hour diet recall scheduled on Saturday and Monday. It is anticipated that each of the sub study visits will last between 40-60 minutes.

The physical activity part of the study will be completed at the same time as the diet sub-study. You will wear a step counter during the day while awake during 3 days just before coming back to the clinic for 3 of the 24-hour diet recall interviews. Each time, the step counter will be mailed to you along with a log where you will write down the number of steps at the end of each day. You will bring the step counter and log to the clinic with you when you come in for the visit. You will answer a few questions about your recent physical activity at the visit. Putting on the step counter and keeping track of the number of steps will take less than 10 minutes each day. Answering the questions will take about 5 minutes at the clinic visit.

Are they any risks I should know about?

Questions are safe and you should not experience any risks by participating in this sub-study. There is no pain or discomfort associated with wearing the step counter. You may find it inconvenient to wear the
step counter and write down the number each day. Other people may notice the step counter and ask you about it.

**Will this cost me anything? Will I receive payment for taking part?**

There is no monetary cost for participation in this sub-study nor will you be paid for participating. Parking is free at the Medical Mall and transportation can be provided if needed.

**What are the benefits of this sub-study?**

The overall benefit of the study is improved knowledge of how diet and physical activity relate to the prevention of coronary heart disease and other medically related problems such as hypertension, obesity, and diabetes. This study will focus on learning about the diets and activity levels of African-Americans. We hope what is learned will help African-Americans reduce their risks for many diseases that are thought to be related to diet and activity.

**Do I have any alternatives?**

Withdrawal from the study can be arranged at my request or due to my lack of participation. My decision not to participate in the diet sub-study will not affect my ability to continue participation in the JHS.

**How can I be sure that my results will be kept confidential?**

Your name will not be mentioned in any report or publications of the study results. You will be told if there are significant developments during the time you are in the study, which might cause you to reconsider continued participation in the sub-study. All your records will be kept confidential. The investigators may give others non-identifying information but will need my written permission to give others information which could identify me personally. If I have any questions about the study, I may call Dr. Herman Taylor at (601) 815-5061, Teresa Carithers at (601) 984-1940 about the diet part, or Dr. Patricia Dubbert (601-364-1350) about the physical activity part.

I may discuss my rights as a research participant with the Chairperson of the University of Mississippi Medical Center’s Institutional Review Board, Dr. Stanley Chapman, 2500 North State Street Jackson, MS 39216, at telephone number: (601) 984-5560.

**Are there any research-related injuries that might occur?**

The University of Mississippi Medical Center has no mechanism to provide compensation for participants who may incur injuries as a result of participating in biomedical or behavioral research. This means that while all investigators will do everything possible in providing careful medical care and safeguards in conducting this research, there is no way in which the institution can pay for the unlikely occurrence of injury resulting solely from the experiment itself. We will, of course provide our best medical treatment to which you are entitled for the illness, if any, for which you consulted us whether or not you participate in this study or whether or not you decide to withdraw from the study.

I _________________________ understand these statements and voluntarily give consent to participate in this research sub-study. A copy of this consent form will be given to me once I have signed it.

____________________________________
Participant                       (Date:)

By signing this document, I, the investigator, enter into a covenant with this participant to maintain the highest standards of scientific conduct in carrying out his research to protect the participant from harm. I
pledge to assure that all participant information is used ONLY for the purposes expressly granted in this consent. Further, I will maintain confidentiality of all participant research information in keeping with the law and federal regulations.

______________________________            (Date:)
Investigator

______________________________ (Date:) __________________________
Witness                                Signature of Person
obtaining informed consent

Name of person obtaining informed consent:

______________________________ (Date:)
Printed Name
## Appendix 6.3 JHS Diet and Physical Activity Sub-study Record of Calls Results Codes

<table>
<thead>
<tr>
<th>Code</th>
<th>Results/Final Disposition</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>No answer</td>
<td>No answer after 5 rings</td>
</tr>
<tr>
<td>B</td>
<td>Busy</td>
<td>Busy signal</td>
</tr>
<tr>
<td>C</td>
<td>Answering Machine</td>
<td>Answering machine</td>
</tr>
<tr>
<td>D</td>
<td>Privacy Block</td>
<td>Phone with privacy block on all calls</td>
</tr>
<tr>
<td>E</td>
<td>Disconnected/non-working #</td>
<td>Recording from phone company or a fast busy signal.</td>
</tr>
<tr>
<td>F</td>
<td>Recording; # changed</td>
<td>Recording from phone company of number changed. Record new number in notes section and retry</td>
</tr>
<tr>
<td>G</td>
<td>Not a residence</td>
<td>Person answering identifies the phone Number as a business. Use or institutions (government offices, educational facilities, health care facilities, etc.) as well as for pagers, fax machines, and computer modems</td>
</tr>
<tr>
<td>H</td>
<td>Household name does not live here/never heard of</td>
<td>Phone answered, name does not reside here or deny knowledge of name</td>
</tr>
<tr>
<td>I</td>
<td>Household name lived here, but moved permanently</td>
<td>Phone answered, person has moved permanently</td>
</tr>
<tr>
<td>J</td>
<td>Household name lives here, temporarily away</td>
<td>Phone answered, person away, but does live in household. Screen eligible respondent.</td>
</tr>
<tr>
<td>K</td>
<td>Household name deceased</td>
<td>Phone answered, person deceased</td>
</tr>
<tr>
<td>L</td>
<td>No eligible household respondent at home</td>
<td>Phone answered, no one eligible to respond in household</td>
</tr>
<tr>
<td>M</td>
<td>Language barrier</td>
<td>Respondent does not speak English well enough to complete screening</td>
</tr>
<tr>
<td>N</td>
<td>Respondent unable to communicate</td>
<td>Use for physical/mental impediment To communication (e.g. slurred speech, hearing impaired, unable to understand questions).</td>
</tr>
<tr>
<td>O</td>
<td>Eligible respondent contacted, screening incomplete</td>
<td>Screening partially completed.</td>
</tr>
<tr>
<td>P</td>
<td>Eligible respondent contacted; Refusal</td>
<td>Terminal code. Refused to complete screening</td>
</tr>
<tr>
<td>Q</td>
<td>Eligible respondent contacted, screening complete</td>
<td>Terminal code, screening complete</td>
</tr>
<tr>
<td>R</td>
<td>Age/race ineligible</td>
<td>Not eligible for JHS because of age/race</td>
</tr>
<tr>
<td>S</td>
<td>Other</td>
<td>Specify in notes</td>
</tr>
<tr>
<td>T</td>
<td>Call Back</td>
<td>Participant stated – would accept call back within 4 to 6 months</td>
</tr>
</tbody>
</table>
Appendix 6.4  Diet and Physical Activity Sub-study Appointment Reminder Letter

JHS Letterhead stationary

Date

Name and Address

Dear

Thank you for taking part in the Diet and Physical Activity Sub study of the Jackson Heart Study. An appointment has been made for you at the Jackson Medical Mall offices of the JHS (address and telephone number noted above) at _____am/pm on ___________.

On the day of your visit, please follow your usual pattern of eating and exercise. You will complete a 24-hour dietary recall and you will answer a few questions about your physical activity for the past week. Please bring all your medications and/or diet supplements including herbal preparations and vitamins or minerals with you to your clinic appointment.

If for any reason you find that you are unable to keep your clinic appointment. Please call at 815-5050 in advance so that substitute appointments can be made.

Thank you once again for your interest in this study.

Sincerely,

Teresa Carithers, RD, LD, MHS, Co PI
Patricia Dubbert, PhD, Co PI
Appendix 6.5  Instructions For Wearing Step Counter

JHS logo

INSTRUCTIONS FOR WEARING STEP COUNTER

1. Please wear the step counter for 3 days during the week before you come in to the clinic for your visit.

2. On the evening before the first day you are going to wear the counter, open the case and set the counter to 0. Close the case and put the counter where you will remember to put it on when you dress in the morning.

3. Put the counter on your waistband or belt as soon as you are dressed and wear it until you are ready to go to bed.

4. Remove the counter when you sleep, bathe, or swim. Check the step counter when you adjust your clothing or use the toilet so it does not fall off.

5. Pin the counter to your belt or waistband for extra security.

6. At the end of the day, open the case and write down the COUNT on the other side of this form. Circle the day of the week and write in the date. Push the button to reset the counter to 0.

7. When you go to bed, keep this log on the same table where you store your step counter.

8. If you forget to wear the step counter for part of a day, do not record the count for that day. Reset the counter to 0 and wait until the next morning to begin a new complete day.

9. If you forget to reset the counter in the evening, you can let it keep on counting until the end of the next day. Make a note that the count is for two days (see COMMENTS).

10. Bring the step counter and this form with your step counts to the clinic with you when you come for your visit.