APPENDIX B

Instructions for Mortality/morbidity Surveillance Data Forms
APPENDIX 12
Instructions for Death Certificate Form

The Death Certificate Form is completed for each eligible death. The purpose of this form is to obtain information on the decedent and information on the informant, coroner/medical examiner, or certifying physician. The ID number has 6 digits, it is the participant’s SHS ID. The community code has 3 digits, it is the standard IHS community code.

Item Instructions

1. Decedent’s name. Enter the first, middle, and last name of the decedent. Begin each name in the left-most box using CAPITAL letters.

2. Death certificate number. This number will be found stamped or typed on the death certificate. If a computer printout is used, it must include this information. Record the number starting in the right-most box. DO NOT add zero to the right of the number.

3. Sex. Record the decedent’s sex.

4. Race. Record as is stated.

5. Marital status. Record as listed. If the death certificate just says "not married" or "S", record as "Single".

6. Date of birth. Record as listed on the death certificate.

7. Date of death. Record as listed on the death certificate.

8. Time of death. Convert all time to 24 hour clock and record. Enter unknown as "=" in each field.

9. Location of death. Choose an appropriate answer. Other includes nursing home, another residence, or a non-hospital institution.

10. Autopsy. Record as indicated on the death certificate.

11. Record whether this is a coroner’s or medical examiner’s case.

12. Interval of onset of symptoms and death. Record the shortest possible category for the immediate cause of death as indicated on the death certificate. If this is missing, DO NOT substitute the interval for another cause. Instantaneous should be recorded as "5 minutes or less".

13. Date abstract completed. Record the date the Death Certificate Form is completed.

14. Code number of abstractor. The field center staff member who has completed this form must enter his/her valid Strong Heart Study code number in this question.
APPENDIX  13

INFORMANT INTERVIEW FORM INSTRUCTIONS

I. General Instructions

The purpose of the informant interview is to obtain information about possible cardiovascular events in order to classify the cause of death. The interview with next-of-kin is potentially difficult because of the sensitive nature of a relative's death and the difficulty recalling or understanding the events related to the death. Even if the informant initially claims no knowledge, begin the form to see if the questions can be answered.

The interviewer should enter the information required on the first page before the contact is made with the informant, though some of the informant data may need to be filled after contact, such as relationship to the decedent. In some cases the informant may change after calling, as in the case where a spouse is to be contacted but the actual informant is a son or daughter. A record of calls should be maintained for the attempts at contacting the informant. The interviewer should put the date and time of each call, any explanatory notes, a result code for each call, and the interviewer's assigned code number. Eight attempts to contact an informant should be made over a two-week period. If no contact is made, attempts can be stopped.

The questionnaire is divided into sections. The first is concerned with the decedent's medical history, including previous hospitalizations, followed by their health in the year prior to date. Then the questions address the events immediately surrounding the fatal event, and the symptoms the deceased experienced prior to the event. Then emergency medical care is ascertained, and the information about other potential informants is requested. A detailed, verbatim, description of the circumstances surrounding death is sought. Finally the interviewer is asked questions about the reliability of the information obtained during the interview.

Almost all questions have multiple choices for answers; however, if necessary the interviewer can write any additional information or comments that may be important to understanding the response in the margins next to the question. A few questions require the interviewer to write out descriptions of the death or the decedent's state of health as related by the informant. For these questions, the interviewer should write word-for-word (in short phrases, abbreviating) the response of the informant. For questions asking the informant to specify names, if more than one answer is given, write all responses.

The interviewer needs to know thoroughly the SHS definition of death to complete the interview accurately. "Death" is defined as the point at which the decedent stops breathing on his/her own and never recovers. Thus, the onset of death for someone who is resuscitated or ventilated is the point at which he/she last breathes spontaneously. He/she may recover several times after resuscitation, but the last cessation of breathing is considered "death". Death is not the time "pronounced dead". If someone is "found dead", timing of death may be estimable if the time since last seen alive was short. However, if long, timing of death may be unknown.
The interviewer should be familiar with skip patterns and the nature of each question. Several questions are similar, with only subtle differences. The interviewer must make the distinction clear to the informant. Such questions may sound repetitive and are easier if clarified.

If the informant contradicts a previous answer, probe to clarify and correct the answers.

If the informant says at the start of the interview that he/she does not know anything about the death, coax the informant to start the interview and try to complete it. If the informant is obviously not helpful, gracefully end the interview.

Written releases need to be witnessed.

Finally, the interviewer is responsible for reviewing and editing the Informant Interview Form thoroughly following the interview. Review every question and the skip patterns carefully. Every question must be answered unless skip patterns indicate otherwise. The description of the events preceding the death is extremely important for diagnostic purposes. Make sure that the description includes the timing of events and the symptoms experienced.

II. Detailed Instructions for Various Questions

ITEM DESCRIPTIONS

1-4 Information on the decedent's name, date of death, and informant should be filled out prior to the informant interview.

5 This question asks for the relationship of the informant to the decedent. Make sure not to reverse this: for example, "She was my mother" should be answered "daughter/son". "Other relative" includes aunt, uncle, cousin, in-law, and grandparent.

6-8 These questions relate to the decedent’s medical history and thus are "ever" questions.

6 This question refers to chest pain from heart disease at any time before death. Angina or angina pectoris or a heart attack would be considered "yes" responses. Pain in the left arm or shoulder, jaw, or upper abdomen is considered equivalent to chest pain.

7 Refer to the list of names for nitroglycerin if informant hesitates. Nitroglycerin is usually administered as a small tablet placed under the tongue but may be taken as a pill, an ointment, or as "skin patch".

8 These questions simply ask whether the decedent had ever had any of these cardiac events previously. Mark the appropriate response for each one.
Synonyms for heart attack are "myocardial infarction", "MI", coronary occlusion.

Coronary bypass involves surgery bypassing the blocked coronary arteries with vessels removed from the arm or leg. "Balloon dilation" or "PCTA" are other terms for angioplasty. A cardiac catheterization, coronary angiography, or angiogram for diagnostic purposes without angioplasty should be answered "no".

A stroke is a brain hemorrhage or ischemia (blockage of blood flow) also known as a cerebrovascular attack, cerebral hemorrhage, or blood clot on brain.

These events include the final, fatal event under consideration.

9-12 These questions relate to hospitalization and doctor’s visits in the year prior to death.

13 If decedent was hospitalized more than once or stayed in more than 1 hospital, record the most recent on the form, then list all dates, names, cities and states of other hospitalizations on a separate piece of paper. If exact dates are unknown, fill in month and year. Missing values are indicated by "=" (equal sign) in the appropriate field.

14 Refer to any encounter with a physician for any reason in the year preceding death, including final symptoms.

15 This should be the most recent visit. If more than one physician was seen, obtain the names and addresses of the two who the respondent thinks would be the most knowledgeable about the decedent.

16 Record the name and address of decedent’s "usual" physician. If the same as most recently seen, record "same".

17 This question refers to any restriction from the decedent’s usually day-to-day activities. It excludes the events at death.

18 "Being cared for" refers to attendant medical care because of disability or sickness.

19 Fill in as much information as is known by informant. If the informant asks why this is needed, explain that it may be important to get additional information from the nursing home, with permission, to understand the cause of death.

20 "Present" is defined as being within sight or sound of the deceased at the time of death; for example, Present: lying next to in bed, in next room and could be heard, left decedent alone momentarily. Not present: in another room out of sight and sound, outside out of sight and sound, left decedent alive and returned after 5 minutes, talked to on phone sometime right before.

21 This question asks whether anyone was present at the time of the decedent’s death (defined above).
If the decedent died in his/her sleep with someone nearby, Question 21 should be answered "yes".

22 Mark the shortest interval known to be reliable. If the informant hesitates, read the intervals in order starting with the shortest.

We are primarily interested in acute symptoms, not chronic. Thus, if a person had been generally fatigued for a month and then had chest pain one hour before death, it is the chest pain that was the last episode. Similarly, if someone had a long history of angina but, not having acute pain, suddenly collapsed and stopped breathing, the onset of the final episode was the time of collapse. If the death occurred while sleeping or while someone was within hearing range of decedent, the interval between onset and death is considered to be instantaneous. If the decedent was found dead (no one close enough to see or hear him/her), the onset may be unknown.

Onset of last episode is defined as being at that point in time when new symptoms cause a change in activity. If the symptom is chronic (e.g., longstanding exertional chest pain), there must be a change in severity or frequency. Symptoms might be step-wise (e.g., one chest pain, then a more severe one an hour later). In this case it is the first pain, if it was new and caused a change, that is the onset of the final episode. The final episode for someone who collapses, is revived, and collapses again began at the first collapse. Interviewers will have to probe and define onset specifically for each informant.

23-24 The location of the pain or discomfort referred to in Q23 and Q24 is specific. If the pain was experienced at sites other than the chest, left arm or shoulder or jaw, the answer should be "no". If the informant is unsure, but is leaning toward a "yes", then proceed as with a "yes". If the decedent was found dead, most of the answers to the next few questions will be "unknown". In this case, skip quickly through, verifying that the answers are unknown.

25 A list of names of "nitroglycerin" preparations is provided in the medication list and should be consulted if informant isn't sure or offers a brand name.

26 This is a crucial question for the timing of death. Use the definition provided above for death and onset of the final episode in order to clarify timing. Read the question, wait for response, and mark the shortest interval known to be true. If the informant gave a time interval when answering Question 23, the interviewer may want to preface Q26 stating the time interval and asking for confirmation (e.g. "You mentioned that _______ had chest pains two days before he died. Is that when the chest pain began?").

27 This question asks about any symptoms other than pain or discomfort in the chest that started within 3 days of death. Make sure the onset was within 3 days, and that the condition was not longstanding or "usual". Read the list slowly and fill in the appropriate answers.

28 Fill in the appropriate response.
29 Fill in as much of the information as is known.

30 This question asks if there is any person who may be able to provide additional information about the events leading up to the death or the death itself. For example, a spouse may know most about the three days prior to death while a co-worker actually witnessed the death. (Note: If the answer is "yes", an interview will need to be carried out with this individual.)

This section is **very important**, and as much detailed information as possible should be sought.

31 Narrative: Write out as close to word-for-word as possible, using short phrases. Probe neutrally for symptoms, order and timing of events, medical care, etc. Record these important items verbatim; try to limit the narrative to the space provided. When describing the events surrounding the death itself, be sure to differentiate between the onset of the last symptoms, the death (recalling definition of death), and being "pronounced dead".

32 Close the interview by thanking the informant and repeating how much the quality of our research depends on the cooperation of people like themselves. After closing the interview, fill in the questions about reliability and administrative information.

If informant is decedent's next of kin and agrees to provide consent for further information, ask him/her to sign the consent form.

33 Interviewer evaluate the quality of information provided by the informant.
APPENDIX  C

Mortality Surveillance Data Forms
THE STRONG HEART STUDY III  
CARDIOVASCULAR DISEASE IN AMERICAN INDIANS

Mortality Survey  
Death Certificate Form

<table>
<thead>
<tr>
<th>ID number:</th>
<th>Community Code:</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Social Security Number:</th>
</tr>
</thead>
</table>

1. Decedent:  
a. Last name: |  
b. Middle name: |  
c. First name: |

2. Death certificate number: (State File Number) |

3. Sex:  
   Male |  
   Female |

4. Race/Ethnicity:  
   American Indian |  
   Hispanic |  
   White |  
   Black |  
   Oriental |  
   Other |  
   Unknown |

5. Marital status:  
   Married |  
   Single |  
   Separated |  
   Divorced |  
   Widowed |  
   Unknown |

6. Date of birth:  
   mo |  
   day |  
   yr |

7. Date of death:  
   mo |  
   day |  
   yr |

8. Time of death (24 hour clock): (if "Death Occurred" is missing use "Death Pronounced")  
   hr |  
   min |

9. Where did the decedent die?  
   IHS hospital/clinic in study area |  
   Non-IHS hospital in study area |  
   Hospital out of area |  
   Home |  
   Other |  
   Location unknown |

10. Was an autopsy performed?  
   Yes |  
   No |  
   Unknown |

11. Was this a coroner's or medical examiner's case?  
   Yes |  
   No |  
   Unknown |

12. Interval between onset and death (for immediate cause of death):  
   5 min. or less |  
   1 hour or less |  
   1 day or less |  
   Unknown or not recorded |  
   1 week or less |  
   1 month or less |  
   more than 1 month |

13. Date abstract completed:  
   mo |  
   day |  
   yr |

14. Code number of abstractor completing this form:  
   |
Mortality Survey
Informant Interview Form

ID number: 

Social Security Number: 

A. DECEDENT (filled by study center staff prior to interview)
1. Name: ________________________
   Last    First    Middle

2. Date of death: ________________________
   mo    /    day    /    yr

B. INFORMANT (filled by study center staff prior to interview)
3. 
   a. Name: ________________________
      Last    First    Middle

   b. Address: ________________________

   c. Telephone: (   ) ________________________

C. RECORD OF CALLS or HOME VISIT TO COMPLETE INTERVIEW

<table>
<thead>
<tr>
<th>DATE (mo/day/yr)</th>
<th>TIME (24 hr clock)</th>
<th>Method of contact</th>
<th>Contact successful</th>
<th>Interview Completed</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
<td>1=Phone</td>
<td>1=Yes</td>
<td>1=Yes</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>2=Home Visit</td>
<td>2=No</td>
<td>2=No</td>
</tr>
<tr>
<td>3</td>
<td></td>
<td>3=Other</td>
<td></td>
<td>9=Refused</td>
</tr>
</tbody>
</table>

1) ________________________
2) ________________________

D. Person Providing Information (filled by study center staff prior to interview).
4. 
   a. Name: ________________________
      Last    First    Middle

   b. Address: ________________________

   c. Telephone: (   ) ________________________

5. Before we get started, could you please tell me what was your relationship to the deceased?
You are the ________________________ Of the deceased.
6. Before his/her final illness, had he/she ever had pains in the chest from heart disease, for example, angina pectoris?
   Yes [ ] 1  No [ ] 2 (If no, go to Q8)  Unknown [ ] 9

7. Did he/she ever take nitroglycerin for this pain?
   Yes [ ] 1  No [ ] 2  Unknown [ ] 9

8. Did he/she ever have any of the following medical condition or procedures before his/her final illness?
   a. heart attack? [ ] 1  [ ] 2  [ ] 9
   b. stroke? [ ] 1  [ ] 2  [ ] 9
   c. heart failure? [ ] 1  [ ] 2  [ ] 9
   d. rheumatic heart disease? [ ] 1  [ ] 2  [ ] 9
   e. any other heart disease or heart condition [ ] 1  [ ] 2  [ ] 9
      If yes, specify: ________________________________
   f. coronary bypass surgery (CABBAGE) [ ] 1  [ ] 2  [ ] 9
   g. coronary angioplasty (balloon angioplasty) [ ] 1  [ ] 2  [ ] 9
   h. insertion of pace maker (defibrillator) [ ] 1  [ ] 2  [ ] 9
   i. any other heart surgery? [ ] 1  [ ] 2  [ ] 9

The next few questions are about his/her health in the year prior to death.

9. Was he/she hospitalized... Yes No Unknown
   In the year prior to death? [ ] 1  [ ] 2  [ ] 9
   In the month prior to death? [ ] 1  [ ] 2  [ ] 9
   In the 7 days prior to death? [ ] 1  [ ] 2  [ ] 9

10. Were any hospitalizations for heart attack or chest pain? Yes [ ] 1  No [ ] 2  Unknown [ ] 9

11. Was a hospitalization for heart surgery? Yes [ ] 1  No [ ] 2  Unknown [ ] 9

12. What was the date of the last hospital admission?
    (If unknown, draw two lines across the boxes)
    __________/_________/[______]  yr

   If the information in questions 13 - 16 is already known to you, skip to Q17.

13. Can you tell me the name and location of the hospital? (If unknown, check the box) [ ]
   a. Name: ________________________________
   b. Address: ________________________________
      City/town: ________________________________
      State-Zip: ________________________________

14. Was he/she seen by a physician anytime in the year prior to death? Yes [ ] 1  No [ ] 2  Unknown [ ] 9

15. Can you tell me the name and address of this physician or healthcare facility? IHS only
   a. Name: ________________________________
   b. Address: ________________________________
      City/town: ________________________________
      State-Zip: ________________________________
16. Can you tell me the name and address of his/her usual physician or healthcare facility. 
If same as Q17, check here. 
   a. Name: ____________________________________________
   b. Address: ____________________________________________
      City/town: ____________________________________________
      State-Zip: ____________________________________________

17. Now, think back to about one month before he/she died. At that time, was he/she sick or ill; 
was his/her activities limited, or was he/she normally active for the most part? 
   Sick/ill/limited activities [___]1  Normally active [___]2  Unknown [___]9

18. Was he/she being cared for at a nursing home, or at another place at the time of death? 
   Yes, nursing home [___]1  No [___]4  
   Yes, at home [___]2  Unknown [___]9 
   Yes, other, specify: ______________________________________________

19. If the decedent was cared by nursing home prior to the death, please tell me the name 
and location of the nursing home:
   a. Name: ____________________________________________
   b. Address: ____________________________________________
   c. Telephone: ( ) ________________________________________

20. Were you present when he/she died? 
   Yes [___]1 (Skip to Q25)  No [___]2  Unknown [___]9

21. If no, how long before he/she died did you last see him/her? 
   1 hour or less [___]1  More than 24 hours [___]2 
   24 hours or less [___]2  Unknown [___]9

Did anyone see or hear him/her when he/she died? 
   Yes [___]1  No [___]2  Unknown [___]9

22. How long after he/she was last known to be alive was he/she found dead?  
(Enter the shortest interval known to be true) 
   5 minutes or less [___]1  More than 24 hours [___]4 
   1 hour or less [___]2  Unknown [___]9 
   24 hours or less [___]3

23. Did he/she experience pain or discomfort in his/her chest, left arm or shoulder or jaw either just 
before death or within 3 days (72 hours) of death? 
   Yes [___]1  No [___]2  Unknown [___]9  
   (If No or Unknown, skip to Q29)
The next set of questions deal specifically with the last episode (that led to the death) of his/her pain or discomfort. The last episode is defined as starting at the time he/she noticed discomfort that caused him/her to stop or change what he/she was doing.

24. Did his/her last episode of pain or discomfort specifically involve the chest?  
   Yes [___] 1  No [___] 2  Unknown [___] 9

25. Did he/she take nitroglycerine because of this last episode of pain or discomfort?  
   Yes [___] 1  No [___] 2  Unknown [___] 9

26. How long was it from the beginning of his/her last episode of pain or discomfort to the time he/she stopped breathing on his/her own?  
   (use the shortest interval known to be true)  
   5 minutes or less [___] 1  24 hours or less [___] 4  
   10 minutes or less [___] 2  More than 24 hours [___] 5  
   1 hour or less [___] 3  Unknown [___] 9

27. Within 3 days of death, or just before he/she died, did any of the following symptoms begin for the first time:  
   a. Shortness of breath? [___] 1  [___] 2  [___] 9  
   b. Dizziness? [___] 1  [___] 2  [___] 9  
   c. Palpitations (pounding in the chest)? [___] 1  [___] 2  [___] 9  
   d. Marked or increased fatigue, tiredness, or weakness? [___] 1  [___] 2  [___] 9  
   e. Headache? [___] 1  [___] 2  [___] 9  
   f. Sweating? [___] 1  [___] 2  [___] 9  
   g. Paralysis? [___] 1  [___] 2  [___] 9  
   h. Loss of speech? [___] 1  [___] 2  [___] 9  
   i. Attack of indigestion or nausea or vomiting? [___] 1  [___] 2  [___] 9  
   j. Other? specify: ____________________________________________ [___] 1  [___] 2  [___] 9

The next few questions are concerned with emergency medical care he/she may have received just prior to or at the time of death. You may have already given this information in an answer to an earlier question. Since it is important to obtain information specifically on emergency medical care, I hope you don't mind if these questions seem repetitive.

28. Was he/she taken to a hospital?  
   Yes [___] 1  No [___] 2

29. If Yes, could you tell me the name and location of this hospital:  
   a. Name: ____________________________________________________
   b. Address: ____________________________________________________
      City/town: ___________________________________________________
      State-Zip: ___________________________________________________

30. Is there someone else whom we could contact, who might know more about the circumstances surrounding his/her death or his/her usual state of health?  
   Yes [___] 1  No [___] 2  Unknown [___] 9  
   (If Yes, complete the front of the second Informant Interview)
31. Finally, I want to ask you to tell me everything about the circumstances surrounding his/her death. Specifically, please tell me what you know of his/her general health, health on the day he/she died, and of the death itself. *(Record summary verbatim)*

---

32. Did informant agreed to provide consent to gather further information?
   - Yes [ ]
   - No [ ]
   - Not applicable [ ]
   *(If Yes, ask the informant to sign the consent form for us to review the decedent's medical records)*

33. How reliable was the participant in completing the questionnaire?
   - Very reliable [ ]
   - Reliable [ ]
   - Unreliable [ ]
   - Very unreliable [ ]
   - Uncertain [ ]

34. Interviewer number: [ ]

35. Date of interview: [ ]
   - mo [ ]
   - day [ ]
   - yr [ ]

*Interview is over, go to Q36. To be completed immediately after the interview.*
THE STRONG HEART STUDY III
Mortality Survey
FINAL DECISION FORM I — AUTOPSY REPORT FORM

ID number:  

Social Security Number:  

1. Decedent’s name:
   a. Last name: 
   b. Middle name: 
   c. First name: 

2. Cause of death, choose appropriate one:
   01 = Definite fatal myocardial infarction
   02 = Definite sudden death due to coronary heart disease
   03 = Definite fatal coronary heart disease
   04 = Possible fatal coronary heart disease
   05 = Definite fatal stroke
   06 = Possible fatal stroke
   07 = Definite fatal congestive heart failure
   08 = Possible fatal congestive heart failure
   09 = Other fatal cardiovascular diseases; specify:

21 = Malignant neoplasm; specify primary site:

22 = Unintentional injury and adverse effects/motor vehicle accident ICD code

23 = Unintentional injury and adverse effect/all other

24 = Pneumonia and influenza

25 = Chronic obstructive pulmonary disease and allied conditions

26 = Diabetes mellitus

27 = Chronic liver disease and cirrhosis

28 = Suicide

29 = Homicide and legal intervention

30 = Nephritis, nephrotic syndrome and nephrosis

31 = ESRD

32 = Septicemia

33 = HIV/AIDS

88 = Other, specify: ICD code

99 = Can not be determined

Date abstract completed:

Code number of abstractor completing this form:
## STRONG HEART STUDY III
CARdiovascular Disease in American Indians
PHOTOCOPY CHECKLIST FOR MEDICAL RECORDS REVIEW
MORTALITY SURVEILLANCE — CVD and NON-CVD

<table>
<thead>
<tr>
<th>Admission date:</th>
<th>ID Number:</th>
</tr>
</thead>
<tbody>
<tr>
<td>mo/day/yr</td>
<td></td>
</tr>
</tbody>
</table>

For each hospital admission WITHIN the YEAR prior to death, obtaining photocopies of each of the following sections of the medical history (when available) and assemble them for each admission. Be sure that photocopies are legible.

<table>
<thead>
<tr>
<th>YES</th>
<th>NO</th>
<th>DONE, but Report Not Available</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Admission Sheets (Face Sheets)**  
|     |    |                                |

**Admitting History and Physical Exam**  
|     |    |                                |

**Discharge Summary**  
|     |    |                                |

**ECGs (SHS-I and II)**  
|     |    |                                |

**Cardiac Enzyme**  
|     |    |                                |

**Reports of results of:**  
- **Chest X-ray**  
|     |    |                                |
- **Echocardiogram**  
|     |    |                                |
- **Angiogram**  
|     |    |                                |
- **Exercise tolerance test (Treadmill)**  
|     |    |                                |
- **Cardiac catheterization**  
|     |    |                                |
- **CT (CAT) scan**  
|     |    |                                |
- **MRI**  
|     |    |                                |
- **Carotid ultrasound**  
|     |    |                                |
- **Lumbar puncture**  
|     |    |                                |
- **Creatinine**  
|     |    |                                |
- **Liver Function test**  
|     |    |                                |
PHOTOCOPY CHECKLIST FOR MEDICAL RECORDS REVIEW
MORTALITY SURVEILLANCE (continued)

## Mortality Survey — Final Decision Form

**ID number:**

**Date of death:** [___/___/___]  
**Age at death:** [___]  

### Underlying cause of death  

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>01</td>
<td>Definite fatal myocardial infarction</td>
</tr>
<tr>
<td>02</td>
<td>Definite sudden death due to coronary heart disease</td>
</tr>
<tr>
<td>03</td>
<td>Definite fatal coronary heart disease</td>
</tr>
<tr>
<td>04</td>
<td>Possible fatal coronary heart disease</td>
</tr>
<tr>
<td>05</td>
<td>Definite fatal stroke</td>
</tr>
<tr>
<td>06</td>
<td>Possible fatal stroke</td>
</tr>
<tr>
<td>07</td>
<td>Definite fatal congestive heart failure</td>
</tr>
<tr>
<td>08</td>
<td>Possible fatal congestive heart failure</td>
</tr>
<tr>
<td>09</td>
<td>Other fatal cardiovascular diseases</td>
</tr>
</tbody>
</table>

### Contributory cause of death

#### Evidence Code:  

(Up to 3 Codes)

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>01</td>
<td>Pathology Report</td>
</tr>
<tr>
<td>02</td>
<td>Clinical Diagnosis only</td>
</tr>
<tr>
<td>03</td>
<td>Pulmonary function test</td>
</tr>
<tr>
<td>04</td>
<td>Blood glucose test</td>
</tr>
<tr>
<td>05</td>
<td>Abnormal liver function tests</td>
</tr>
<tr>
<td>06</td>
<td>Abnormal kidney function test</td>
</tr>
<tr>
<td>07</td>
<td>Positive culture (blood or sputum)</td>
</tr>
<tr>
<td>08</td>
<td>Positive antibody test</td>
</tr>
<tr>
<td>09</td>
<td>Positive blood test (any type)</td>
</tr>
<tr>
<td>10</td>
<td>Autopsy</td>
</tr>
<tr>
<td>11</td>
<td>Police/Coroner=s investigation</td>
</tr>
<tr>
<td>12</td>
<td>Other medical records evidence</td>
</tr>
</tbody>
</table>

### Specify:

- [ ] Other medical records evidence
- [ ] Autopsy
- [ ] Police/Coroner=s investigation
- [ ] Other medical records evidence

### Was the death alcohol related?  

- [ ] Yes
- [ ] No
- [ ] Unknown
B. Criteria used: (Please check the appropriate boxes)

1. Definite fatal myocardial infarction

[ ] 1)a. Definite MI within 4 weeks of death by criteria:
   
   1. Evolving diagnostic ECG, and/or
      [ ] 1 | [ ] 2
   2. Diagnostic ECG and abnormal cardiac enzymes, and/or
      [ ] 1 | [ ] 2
   3. Prolonged cardiac pain and abnormal cardiac enzymes
      [ ] 1 | [ ] 2

   OR

[ ] 1)b. Acute MI diagnosed by autopsy

AND

[ ] 2) No known non-atherosclerotic or noncardiac-atherosclerotic condition that was probably lethal according to death certificate, autopsy report, hospital records, or physician records.

2. Definite sudden death due to CHD

[ ] 1. Death witnessed as occurring within 1 hour after the onset of severe cardiac symptoms (prolonged cardiac pain, shortness of breath, fainting) or within 1 hour after the subject was last seen without symptoms.

   AND

[ ] 2. No documentation of acute MI within 4 weeks prior to death.

   AND

[ ] 3. No known non-atherosclerotic or noncardiac-atherosclerotic process that was probably lethal according to death certificate, autopsy report, hospital records, or physician report.
3. Definite fatal CHD

[ ] 1. Death certificate with consistent underlying or immediate causes, \textbf{AND}

[ ] 2. No documentation of definite acute MI within 4 weeks prior to death, \textbf{AND}

[ ] 3. Criteria for sudden death not met (above), \textbf{AND}

[ ] 4. No known non-atherosclerotic or noncardiac-atherosclerotic process or event that was probably lethal according to death certificate, autopsy report, hospital records, or physician records, \textbf{AND}

[ ] 5(a) Previous history of MI according to relative, physician, or hospital records, or definite or possible MI by criteria, \textbf{OR}

[ ] 5(b) Autopsy reporting severe atherosclerotic-coronary artery disease or old MI without acute MI (50\% proximal narrowing of two major vessels or 75\% proximal narrowing of one more vessel, if anatomic details given.), \textbf{OR}

[ ] 5(c) Death occurring greater than 1 and less than or equal to 24 hours after the onset of severe cardiac symptoms or after subject was last seen without symptoms, \textbf{OR}

[ ] 5(d) Angiogram reporting severe (≥ 50\% narrowing) atherosclerotic coronary artery disease, \textbf{OR}

[ ] 5(e) Other positive physical signs or lab findings.

4. Possible fatal CHD

[ ] 1. No documentation by criteria of definite acute MI within 4 weeks prior to death, \textbf{AND}

[ ] 2. No documentation by criteria of definite sudden death, \textbf{AND}

[ ] 3. No documentation by criteria of definite fatal CHD, \textbf{AND}

[ ] 4. Death certificate with consistent underlying or immediate cause, \textbf{AND}

[ ] 5. No known non-atherosclerotic or noncardiac-atherosclerotic process that was probably lethal according to death certificate, autopsy report, hospital records, or physician records.
5. Definite fatal stroke (also complete Section C)

[ ] 1a. Cerebral infarction or hemorrhage diagnosed at autopsy,
   **AND**

[ ] 1b. No other known disease process or event such as brain tumor, subdural hematoma, subarachnoid hemorrhage, metabolic disorder, or peripheral lesion that could cause localizing neurologic deficit or coma according to death certificate, autopsy, hospital records, or physician records,

**OR**

[ ] 2a. History of rapid onset (approximately 48 hours from onset to time of admission or maximum acute neurologic deficit) of localizing neurologic deficit and/or change in state of consciousness,
   **AND**

[ ] 2b. Localized neurologic deficit within 6 weeks of death documented by unequivocal physician or laboratory findings with 24 hours duration of objective physician findings,
   **AND**

[ ] 2c. No other known disease process or event such as brain tumor, subdural hematoma, subarachnoid hemorrhage, metabolic disorder, or peripheral lesion that could cause localizing neurologic deficit or coma according to death certificate, autopsy, hospital records, or physician records,

6. Possible fatal stroke (also complete Section C)

[ ] 1. Death certificate with consistent underlying or immediate cause (ICD-9, code 431-437), but neither autopsy evidence nor adequate pre-terminal documentation of the event,
   **AND**

[ ] 2. No evidence at autopsy examination of the brain, if performed, of any disease process that could cause localizing neurologic signs that would not be connected with cerebral infarction or hemorrhage.

7. Definite fatal congestive heart failure.

**Two major criteria or one major and two minor criteria:**

a. Major criteria

[ ] i. Paroxysmal nocturnal dyspnea or Orthopnea
[ ] ii. Neck vein distention
[ ] iii. Rales
[ ] iv. Cardiomegaly
[ ] v. Acute pulmonary edema
[ ] vi. S3 gallop
[ ] vii. Increased venous pressure > 16 cm water
[ ] viii. Circulation time ≥25 seconds
[ ] ix. Hepatojugular reflux
b. Minor criteria
   [ ] i. Ankle edema
   [ ] ii. Night cough
   [ ] iii. Dyspnea on exertion
   [ ] iv. Hepatomegaly
   [ ] v. Vital capacity reduced by one third from maximum
   [ ] vi. Tachycardia (rate of ≥120/min.)

c. Major or minor criteria
   [ ] i. Weight loss > 4.5 kg in 5 days in response to treatment
   AND

d. [ ] No known non cardiac process leading to fluid overload such as renal failure

8. Possible fatal congestive heart failure
   [ ] Death certificate or medical records with consistent underlying or immediate cause, but neither autopsy evidence nor adequate pre-terminal documentation of the event.

9. Other fatal cardiovascular diseases
   [ ] i. Death certificate or medical records with consistent underlying or immediate cause.

Comment: __________________________________________

C. TYPE OF CEREBRAL EVENT:

1. Thrombo-embolic infarction
2. Subarachnoid hemorrhage
3. Intraparenchymal hemorrhage
4. Lacunar infarction
5. Other, unknown infarction
6. TIA
7. Unknown type stroke
D. Does the diagnosis in Section A (Cause of death) agree with your clinical impression? [ ]
   1=Yes    2=No

If "No", what is your diagnosis? ________________________________ [ ]

Why? _______________________________________________________

_____________________________________________________________

Reviewer's code: [ ]

Date completed: [___/___/___]

Coordinating Center Use Only

Reviewed:
   First review [___]   Second review [___]   Third review [___]   Adjudication [___]
<table>
<thead>
<tr>
<th>ID number:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Death Certificate</td>
</tr>
<tr>
<td>2. ICD coded cause of death by nosologist</td>
</tr>
<tr>
<td>3. Autopsy performed</td>
</tr>
<tr>
<td>4. Autopsy report</td>
</tr>
<tr>
<td>5. If autopsy report is available, Autopsy Form (by receiver)</td>
</tr>
<tr>
<td>6. Medical Records Photocopy Checklist</td>
</tr>
<tr>
<td>7. Copy reports as specified</td>
</tr>
<tr>
<td>8. Check if the decedent is eligible for the morbidity survey and proceed as required by the morbidity survey protocol.</td>
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<tr>
<td>9. Check if tracking form was sent.</td>
</tr>
<tr>
<td>10. Informant Interview Form?</td>
</tr>
<tr>
<td>11. Medical Records Abstract Form, Informant Interview Form, Autopsy Autopsy Report Form, and Final Decision Form to Dr. Sievers on Date</td>
</tr>
<tr>
<td>12. Send to Dr. Weber if this is a potential stroke case Date</td>
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</tbody>
</table>

Code number of SHS staff completing this form [_______]

Date completed: [_______] / [_______] / [_______]

Strong Heart Study III - 03/14/97

Mortality Survey Packet Checklist
APPENDIX D

Morbidity Surveillance Data Forms
List all facilities where patient was hospitalized or was an outpatient since date of last SHS contact.

Reason: 1=Heart attack  2=Stroke  3=CHF  4=Other CVD, please specify.  5=Other non-CVD, please specify.

If it is a FATAL event, mark X in the inpatient or outpatient space.

<table>
<thead>
<tr>
<th>Inpatient</th>
<th>Outpatient</th>
<th>Hospital/Clinic</th>
<th>Town/State</th>
<th>Date (mm/dd/yy)</th>
<th>Abstracted Reason (Y/N)</th>
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<tr>
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<td>Diagnosis :</td>
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<td>Diagnosis :</td>
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<td>Diagnosis :</td>
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<tr>
<td>Diagnosis :</td>
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</table>
THE STRONG HEART STUDY III
CARDIOVASCULAR DISEASE IN AMERICAN INDIANS

Morbidity Survey
Medical Records Abstract and Photocopy Checklist for Non-Fatal CVD Events or Procedures

ID number: ____________________________

1. a. Hospital code number: ____________________________
b. Hospital name: ____________________________
c. Hospital location: ____________________________
d. Medical record number: ____________________________

2. Date of ADMISSION to this hospital: 
   mo | day | yr

3. Date of discharge: 
   mo | day | yr

4. Was the patient transferred to or from another acute care hospital?
   Yes [ ]  (be sure information is listed on M&M master list form)  No [ ]

5. Enter the ICD-9 code numbers for the hospital discharge diagnoses and procedure codes recorded in the medical record exactly as they appear on the front sheet of the medical record and/or on the discharge summary. Be sure they are ICD-9 codes. Record diagnoses if no codes are available.

   1. [ ] [ ] [ ] [ ]
   2. [ ] [ ] [ ] [ ]
   3. [ ] [ ] [ ] [ ]
   4. [ ] [ ] [ ] [ ]
   5. [ ] [ ] [ ] [ ]
   6. [ ] [ ] [ ] [ ]
   7. [ ] [ ] [ ] [ ]
   8. [ ] [ ] [ ] [ ]
   9. [ ] [ ] [ ] [ ]
   10. [ ] [ ] [ ] [ ]
   11. [ ] [ ] [ ] [ ]
   12. [ ] [ ] [ ] [ ]
For each hospital admission, obtain photocopies of each of the following sections of the medical records (when available) and assemble them for each admission. Be sure that photocopies are legible.

Admission Sheets (Face Sheets), including Diagnoses
Admitting History and Physical Exam
Discharge Summary
ECGs (see instruction)
Cardiac enzyme report (days 1 to 4)
Neurology Consult Report

Reports of Procedures:
1. Echocardiogram
2. Coronary angiogram
3. Exercise tolerance test (Treadmill)
4. Cardiac catheterization
5. Coronary bypass
6. Coronary angioplasty
7. Swan-Ganz catheterization
8. Intracoronary streptokinase, or TPA reperfusion
9. Intravenous streptokinase, or TPA reperfusion
10. Aortic balloon pump
11. Radionuclide scan
12. Computerized Axis Tomography (CAT or CT) of the head
13. Magnetic Resonance Image (MRI) of the head
14. Carotid ultrasound/Doppler
15. Lumbar puncture
16. Angiography
17. Other, specify: __________________________

Be sure to include Tracking Sheet in the packet

Code number of SHS staff completing this form

Date completed: \[___/___/___\]
THE STRONG HEART STUDY III
Morbidity Survey — DECISION FORM

ID number: ____________________________
Date of this event: ______/____/____

A. DIAGNOSIS (enter appropriate code number):
   01. Definite non-fatal myocardial infarction __________
   02. Possible non-fatal myocardial infarction __________
   03. Definite non-fatal stroke __________
   04. Possible non-fatal stroke __________
   06. Definite CHD __________
   07. Possible CHD __________
   08. TIA __________
   09. Other CVD, specify: ____________________________ __________
   10. Non-CVD, specify: ____________________________ __________

B. Criteria used: (Please check one box in each field)

1. MYOCARDIAL INFARCTION
   a. PROLONGED CARDIAC PAIN
      Present __________
      Absent __________
   b. ECG FINDINGS
      Evolving diagnostic ECG __________
      Diagnostic ECG __________
      Equivocal ECG __________
      Absent, uncodable, or other __________
   c. CARDIAC ENZYMES
      Abnormal __________
      Equivocal __________
      Incomplete __________
      Normal __________
      i) Troponin-I > 0.4 ng/ml
         Yes __________
         No __________
         Not done __________

COMMENTS: ____________________________________________
_____________________________________________________
_____________________________________________________
_____________________________________________________
2. STROKE

a. DIAGNOSTIC EVIDENCE
   Unequivocal physician or laboratory 1
   Discharge diagnoses of stroke (431, 432, 434, 436, 437) 2
   Neither of above 9

b. ONSET/DURATION OF NEUROLOGICAL DEFICIT
   Rapid/ > 24 hours 1
   Rapid/ < 24 hours 2
   Protracted/ > 24 hours 3
   Protracted/ < 24 hours 4

c. OTHER CAUSES
   Present 1
   Absent 2

d. TYPE OF STROKE:
   1. Thrombo-embolic infarction
   2. Subarachnoid hemorrhage
   3. Intraparenchymal hemorrhage
   4. Lacunar infarction
   5. TIA
   6. Other, unknown infarction
   7. Unknown type stroke

COMMENTS:


3. Definite Coronary Heart Disease (CHD)

a. Cardiac cath proven coronary artery disease (1 or more
   vessels \( \geq \) 50% stenosis), or 1
b. PTCA, or 2
   Coronary artery bypass grafting, or 3
   Abnormal stress ECG, and 4
   Abnormal imaging, or 5
   Positive functional test of ischemia (such as treadmill) 6

COMMENTS:


Strong Heart Study III - 11/7/97
CVD Final DX
4. Other Non-fatal Cardiovascular Disease
   a. Congestive Heart Failure
   b. CHF 2 degrees to ESRD (diagnosis = 10)
   c. Cardiomyopathy
   d. Valvular Heart Disease
   e. Left ventricular Hypertrophy
   f. Atrial Fibrillation
   g. Noncoronary heart surgery or carotid or other vascular surgery
   h. Pacemaker implantation
   i. Positive non-coronary angiography
   j. Arrhythmia
   k. Angina pectoris (Class 2 chest pain, or relieved by nitroglycerides)
      (diagnosis = 07)

COMMENTS: ____________________________________________________________

_____________________________________________________________________

_____________________________________________________________________

C. Does the diagnosis in Section A (DIAGNOSIS) agree with your clinical impression?
   Yes [__] 1  No [__] 2

   If No, what is your diagnosis? (Diagnosis in A)
   Why? ______________________________________________________________
   ___________________________________________________________________
   ___________________________________________________________________
   ___________________________________________________________________
   ___________________________________________________________________

Reviewer's code: ________________________________
Date completed: ________________________________

Coordinating Center Use Only

Deposition: Regular [__] 1  QC [__] 2  Equivocal [__] 3  Adjudication [__] 9
THE STRONG HEART STUDY III
CARDIOVASCULAR DISEASE IN AMERICAN INDIANS

Morbidity Survey
Cardiovascular Test Procedures Abstract

ID number: ____________

1. WAS CATHETERIZATION/ANGIOGRAM DONE?
   Yes [ ] 1  No (skip to Q18) [ ] 2  Yes, but no report [ ] 3

2. If YES, When?
   ___/___/___
   mo/day/yr

3. Where:________________________________________
   Hospital/clinic: ____________________________
   City/State: ____________________________
   Hospital Code: ____________________________

Was Any Vessel ≥ 50% Stenotic in ...

4. Left Main:
   Yes [ ] 1  No [ ] 2  Uncertain [ ] 8  Unknown [ ] 9

5. Left anterior descending:
   Yes [ ] 1  No [ ] 2  Uncertain [ ] 8  Unknown [ ] 9

6. Right coronary:
   Yes [ ] 1  No [ ] 2  Uncertain [ ] 8  Unknown [ ] 9

7. Circumflex artery:
   Yes [ ] 1  No [ ] 2  Uncertain [ ] 8  Unknown [ ] 9

8. Ejection Fraction (%):
   777 = normal, % not specified
   999 = unknown/no response
   888 = abnormal, % not specified

9. Left Ventricular Function:
   Normal [ ] 1  Assessed, results not specified [ ] 3
   Depressed [ ] 2  Not assessed (skip to Q18) [ ] 9

10. Was Akinetic Wall Observed?
    Yes [ ] 1  No (skip to Q15) [ ] 2  Uncertain [ ] 8  Unknown [ ] 9

11. Anterior:
    Yes [ ] 1  No [ ] 2  Uncertain [ ] 8  Unknown [ ] 9

12. Inferior:
    Yes [ ] 1  No [ ] 2  Uncertain [ ] 8  Unknown [ ] 9

13. Apex:
    Yes [ ] 1  No [ ] 2  Uncertain [ ] 8  Unknown [ ] 9

14. Diffuse:
    Yes [ ] 1  No [ ] 2  Uncertain [ ] 8  Unknown [ ] 9
Finding of Valvular Function:

15. Mitral regurgitation:  
   Yes | | No | | Uncertain | | Unknown | | 
   1 | | 2 | | 3 | | 4 | | 5 | | 6 | | 7 | | 8 | | 9 | | 

16. Aortic regurgitation:  
   Yes | | No | | Uncertain | | Unknown | | 
   1 | | 2 | | 3 | | 4 | | 5 | | 6 | | 7 | | 8 | | 9 | | 

17. Was Angioplasty performed?  
   Yes | | No | | Uncertain | | Unknown | | 
   1 | | 2 | | 3 | | 4 | | 5 | | 6 | | 7 | | 8 | | 9 | | 

18. WAS TREADMILL EXERCISE TEST DONE?  
   Yes | | No (skip to Q25) | | Yes, but no report | | 
   1 | | 2 | | 3 | | 4 | | 5 | | 6 | | 7 | | 8 | | 9 | | 

19. If YES, When?  
   mo | | day | | yr | | 

20. Where:  
   Hospital/clinic | | City/State | | Hospital Code | | 

21. Treadmill ECG:  
   Normal | | Borderline | | Abnormal | | Inconclusive | | No report | | 
   1 | | 2 | | 3 | | 8 | | 9 | | 

22. Maximum heart rate (beats/minute):  
   999=no report | | 

23. Maximum systolic blood pressure (mmHg):  
   999=no report | | 

24. Treadmill time (round to nearest whole number minute):  
   99=no report | | 

25. WAS THALLIUM TEST, OR OTHER NUCLEAR IMAGE TEST DONE?  
   Yes | | No (skip to Q29) | | Yes, but no report | | 
   1 | | 2 | | 3 | | 4 | | 5 | | 6 | | 7 | | 8 | | 9 | | 

26. If Yes, when?  
   mo | | day | | yr | | 

27. Where:  
   Hospital/clinic | | City/State | | Hospital Code | | 

28. Test results:  
   Positive | | Negative | | Equivocal | | No report | | 
   1 | | 2 | | 3 | | 4 | | 5 | | 6 | | 7 | | 8 | | 9 | | 

29. Reviewer's code:  
   | | 

30. Date completed:  
   mo | | day | | yr | |