2. IDENTIFICATION OF EVENTS

2.1 Introduction

The basic features of the community surveillance design are summarized in Table 1. Events surveyed in each of the four communities include fatal CHD and hospitalized MI (see Appendix I), beginning January, 1987.

Table 1. ARIC Community Surveillance Eligibility Criteria

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Eligibility</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>Between 35 and 74, inclusive</td>
</tr>
<tr>
<td>Race</td>
<td>All races</td>
</tr>
<tr>
<td>Place of residence</td>
<td>Within the defined boundaries of the ARIC communities</td>
</tr>
<tr>
<td>Date of discharge or death</td>
<td>January 1, 1987 - December 31, 1992</td>
</tr>
<tr>
<td>ICD9 Codes for identification of CHD death</td>
<td>250, 401, 402, 410-414, 427-429, 440, 518.4, 798, 799</td>
</tr>
<tr>
<td>ICD9 Codes for identification of hospitalized MI</td>
<td>402, 410-414, 427, 428, 518.4</td>
</tr>
</tbody>
</table>

Events meeting the eligibility criteria given in Table 1 are investigated for conformity with ARIC surveillance diagnostic criteria. Identification of hospitalized events is limited to acute care hospitals in the catchment area (Section 2.2.3); no systematic attempt is made to obtain events from records of nursing homes, mental hospitals, private physicians, or hospitals out of the catchment area.

Hospitalized MIs are documented by ARIC field staff trained to identify ECG Q-waves using the Minnesota Code.

Out-of-hospital deaths (as defined in Section 3.1.2) are documented by means of informant interviews and family physician questionnaires. Coroner/medical examiner records are abstracted when available. Since Maryland laws prohibit the use of information found in death certificates as a means to contact relatives, validation of out-of-hospital deaths in Washington County is not carried out.

Deaths occurring in acute care hospitals are documented by abstracting the medical record, as with all nonfatal events.
The elements of the diagnostic criteria for the various events are abstracted onto standardized data forms. For hospitalized events, the occurrence of MI is determined when possible by computer analysis of the recorded diagnostic elements; for fatal events, cause of death is assigned by computer analysis or a Mortality and Morbidity Classification Committee (MMCC), according to criteria described in Section 4.

Quality control programs are carried out to assess reliability of abstracting medical records, both the reliability and validity of coding ECGs, and the reliability of MMCC procedures.

Two sources of identification of events are used: death certificates and hospital discharge indexes.

2.2 Identification of Hospitalized MI

2.2.1 Obtaining Access to Hospital Medical Records

A critical feature of surveillance is obtaining information from medical records. Without complete cooperation of hospitals, the usefulness of event rates in any community is limited. The following represents an approach for obtaining hospital cooperation which each Field Center adapts to suit the situation existing in its study community.

For the initial contact, a letter briefly describing the study is sent to the hospital administrator and the director of medical records. It is important to keep the director of medical records informed about the project and the progress of the research.

Following the initial letter, a detailed protocol is sent to each hospital administrator. Many hospitals have a medical ethics committee to review research protocols. Within two weeks of sending the protocol, the administrator and director of medical records are contacted to determine if there is difficulty in obtaining permission to review records.

Simultaneously with the submission of the protocol, the heads of cardiology are contacted. A face to face meeting with the cardiologists is important to enlist their cooperation. This may follow one of two formats. One is to arrange to meet individual cardiologists at their respective offices. The second consists of arranging a reception or dinner with the cardiologists in order to describe the study. The contact with the cardiologists is essential so that knowledge of the study is disseminated at each hospital. Moreover, if there is difficulty in obtaining permission to review records, the cardiologists can often assist in the review process.

It is also helpful to address the local medical records committees. Most require continuing education credits. A description of the epidemiologic research which provides the credits is beneficial to both the medical records librarians and the project.
If there appears to be difficulty in obtaining permission, it is important to recontact the hospital administrators, arrange to meet with the administrators and house staff, as well as to offer to meet with the review committee. A critical feature is to emphasize the scientific importance and the non-threatening nature of the research. An additional point for the hospital administrator is to indicate that the research will not impede normal hospital function. It may be helpful for a senior investigator to arrange to meet with the director of medical records to describe the study. The director of medical records often is of considerable help in obtaining permission. These individuals are professionals and recognize the importance of employing medical records in research.

An additional approach which is often successful is to have faculty from the medical school contact the cardiologists. Faculty on the medical school staff who either work in the hospitals or have trained the physicians on the staff can often be very helpful for contact.

A critical reason for refusal is confidentiality of medical records. It is important to be able to respond to this issue. It may help to obtain clarification from the individual States if questions of confidentiality arise.

After permission is received, a senior investigator and the staff who do the abstracting may arrange to meet with the directors of medical records. At this time, the study should be reviewed in addition to describing the role of the medical record departments in the research. It is important to schedule time for the ARIC staff to review the records at periods when the record rooms are not busy. It is essential that the ARIC research staff control the record review.

It is sometimes necessary to compromise with the hospital review committees and house staff. Again, the major consideration is confidentiality. Some hospitals will not permit the abstraction of a patient's name. It is important to obtain the name because this is the surest method to reduce redundancy in the records. However, less optimal procedures are available. The first is to seek permission to code the name and record addresses, social security numbers, and birth dates. If these are available, the likelihood of redundancy can be reduced by sorting lists of individuals by birth dates or social security numbers.

It is important to keep the medical records directors, hospital administrators and cardiologists informed concerning the progress of the project. A periodic newsletter and reprints of publications from the project may help demonstrate the significance of the research and the lack of threat to the hospitals. This is also important because there is turnover in staff both for the researchers and the hospitals, thus the newsletters serve as a reminder to the continuing staff and an introduction to the newly hired staff.
2.2.2 Hospital Discharge Index

Eligible hospitalized MIs are identified from the discharge index of each hospital surveyed. Discharge indices are obtained directly from the hospital or from an indexing service such as the Commission on Professional and Hospital Activities (CPHA).

When a person is discharged from a hospital, the physician must indicate the major illness from which the patient suffers. Usually one such diagnosis accounted for the hospitalization. This is the primary discharge diagnosis. Other old or new diagnoses may be listed as secondary discharge diagnoses. Discharge diagnoses are coded by the hospital medical records personnel according to the International Classification of Diseases (ICD). Most hospitals subscribe to a service which takes these diagnostic codes and produces an index of discharges classified by code.

The ICD was originally constructed to provide comparable international data on causes of death. It is now extended by many countries for use in coding hospital discharge diagnoses. The extension of the ICD currently being used by hospitals is called ICD9-CM (Clinical Modification). The hospital or "CM" modifications do not alter the basic three digit codes, but provide additional codes so that diagnoses may be classified with more detail. For instance, ICD9 uses the code 410 for acute MI: ICD9-CM adds a decimal point so that the location of the MI can be coded (e.g., an anterior wall MI is coded 410.1).

Using the discharge index for each hospital, hospitalized events are selected according to the following eligibility criteria.

1. **Age.** ARIC examines cases only at ages 35 through 74 at time of discharge.

2. **Place of Residence.** Patients must live within the boundaries of the ARIC community. The discharge index may give only Zip Code, in which case a determination of residence eligibility may require checking the address in the hospital records. If a review of the medical record indicates the person was only visiting the area or had two residences, the address where the person lived at least six months of the year is considered the place of residence for ARIC purposes. People residing in a local jail at the time of hospitalization are counted.

3. **Date.** Time eligibility is determined from the date of discharge. Only cases discharged after January 1, 1987 are eligible.

4. **ICD9-CM Code.** Cases with primary or secondary diagnoses with ICD9-CM codes 402, 410-414, 427, 428 and 518.4 are selected for documentation of hospitalized MI.

The number of cases meeting these four eligibility criteria is reduced by applying various sampling fractions to different classes of ICD9-CM codes.
1. **Code 410.** 100% sample.

2. **Code 411.** 50% sample, when the record does not have a 410 code. The 50% sample is selected by choosing only the events with discharges occurring on even days of the month, i.e., days 2, 4, 6, etc.

3. **Codes 412-414.** 25% sample, when the record does not have a 410 or 411 code. The 25% sample is selected by choosing only the events with discharges occurring on days of the month divisible by 4, i.e., days 4, 8, 12, 16, 20, 24 and 28.

4. **Codes 402, 427, 428 and 518.4.** 10% sample, when the record does not have a 410-414 code. The 10% sample is selected by choosing only the events with discharges occurring on days of the month divisible by 8, i.e., days 8, 16 and 24.

These sampling fractions are reassessed one year after community surveillance starts.

ICD codes listed on the hospital discharge index may not exactly correspond with those found in the corresponding hospital chart. Regardless, it is the codes listed on the discharge index which determine eligibility for selection and which are used to classify events.

2.2.3 **MIs Occurring Outside the Study Community**

Community residents with MI may be hospitalized out of the study area for the following reasons:

1. A major hospital catchment area for the region exists outside of the study area (e.g., tertiary care hospital referral centers).

2. Residents who work outside of the geographic area may be admitted to an out-of-area hospital if they have an MI at work.

3. A resident may have an event while in transit outside of the geographic area for recreation or social activities.

In order to select hospitals outside of the study area to include in surveillance, the Field Center first identifies those hospitals which are located in the surrounding areas. Second, the center determines by checking with local physicians, cardiologists, hospital administrators and others whether patients with acute MI are usually hospitalized locally prior to admission to a tertiary care facility outside the study area. Third, 1984 and 1985 death certificates for study area residents are reviewed. Surveillance is carried out in any hospital outside of the geographic area that contributed at least six eligible in-hospital MI deaths (ICD9-CM 410-414) in the 1984-1985 period. Major medical centers or tertiary referral facilities some distance from the study area are not included in surveillance unless there is evidence that patients with acute MI from the study area are directly admitted to such hospitals without treatment at a within-area
hospital. Selection of hospitals included in community surveillance is reassessed during the fourth year of the study.

Community residents hospitalized with acute MI while outside both the study area and the surrounding counties are not identified by routine surveillance. An estimate of the effect of this procedure is available from the surveillance for hospitalized events in cohort members.

2.2.4 Range of Facilities Covered in Surveillance

Hospitalized MI patients are identified by review of records only at acute care hospitals. Nursing homes, rehabilitation hospitals, long-term chronic disease hospitals, and psychiatric hospitals are excluded. A small number of MI patients hospitalized at these chronic care facilities for another disease, e.g., multiple sclerosis, peripheral vascular disease, diabetes, etc., may have an acute MI while in the chronic care facility and not be referred to an acute care facility or may die before referral. These individuals are lost to the surveillance system. Such an event is probably rare and would be difficult to identify from review of chronic care facility records.

Community surveillance does not identify nonfatal MI occurring outside of a hospital and for which the individual is not hospitalized (unrecognized MI).

2.3 Identification of CHD Deaths

2.3.1 Death Certificates

All deaths in the United States must be recorded on a death certificate which is filled out by a physician, medical examiner or coroner. The death certificate is a legally mandated, public document which is filed in the county of the decedent's residence. A copy is filed with the state. If a person dies away from his usual residence, a copy of the death certificate is (eventually) returned to the decedent's county of residence for filing and is also filed at the state health department. In each state, health department trained nosologists code the causes of death given on the death certificate according to the International Classification of Diseases (ICD). The 9th revision of the ICD (termed ICD9) is currently used.

Each of the four states containing the ARIC communities assigns the specific "underlying cause of death" from the nosologist's coding of the death certificate using the Automated Classification of Medical Entities (ACME) system. Computer files, which include the date of death, underlying cause, decedent's age and residence, are available. Each center obtains a monthly printout of potentially eligible cases based on the criteria listed below. The monthly printouts generally contain in-state deaths that occurred three to five months previously. In addition, all four centers annually obtain a final computer tape of eligible deaths to verify that ascertainment is complete and to provide numerators for rate calculations.
Fatal events are selected according to the following eligibility criteria.

1. **Age.** ARIC examines deaths only at ages 35 to 74.

2. **Place of Residence.** The decedent must have lived within the boundaries of the ARIC community. The residence at death determines eligibility. However, if it is found in event investigation that the decedent was only visiting the area, or had two residences, the place where the person lived at least six months out of the year is considered the residence for ARIC purposes. Do not count anonymous "John Doe" deaths. But do count people residing in a local jail at the time of death.

3. **Date.** Only deaths occurring from January 1, 1987 through December 31, 1992 are eligible.

4. **ICD9 Code.** Deaths whose underlying cause is coded (using ICD9) 250, 401, 402, 410-414, 427-429, 440, 518.4, 798 and 799 are selected for documentation of MI or CHD.

Copies of death certificates for the potential fatal events identified on the monthly printouts are obtained from the respective State Departments of Health. Abstractors review each certificate to confirm the death meets age, residency, date, and ICD9 code criteria. ARIC cohort members are identified by comparison with the cohort clinic roster and other criteria outlined in Section 1.10 of Manual 2. The remaining fatal cases are reduced in number by applying various sampling fractions to different classes of ICD9 codes. These constitute the deaths to be investigated:

1. **Codes 410-414 and 429.2.** 100% sample.

2. **Codes 250, 401, 402, 427-429 (except 429.2), 440, 518.4, 798 and 799.** 25% sample. For a 25% sample of cases, only deaths occurring on days of the month divisible by 4 are selected for further investigation.

A Surveillance Event Eligibility Form (Appendix II) is completed for each event to help with sample selection. An ID number is assigned to each event, a Death Certificate Form (DTH) (Appendix II) is completed (see Section 3.1), and the death certificate is filed locally.

2.3.2 CHD Deaths Occurring Outside the Study Community

For fatal hospitalized events, the address on the death certificate takes precedence over the address in the hospital record for determining eligibility.
Deaths outside of the study area, but within the state, are included on State Health Department monthly printouts, but some delay between the death and the transfer of the certificate to the place of residence file is expected. If the death certificate file is reviewed for ARIC prior to receipt of out-of-area certificates, subsequent review is undertaken to identify in-transfer deaths.

Deaths that occurred in other states are relatively few in the ARIC study areas which do not closely border another state. The out-of-state deaths cannot be identified in a timely fashion but can be identified on the annual mortality computer tapes provided by the State Health Departments. Access to identifiers for out-of-state deaths is restricted. For these reasons, out-of-state deaths will only be enumerated from vital records and not investigated further.