



## INSTRUCTIONS FOR THE DEATH INFORMATION QxQ (10/22/2020) (DEC, VERSION 1, 01/05/2015)

### I. General Instructions

This form is completed under two circumstances:

- a) During the course of a scheduled semi-annual interview, the proxy respondent or contact reports that the participant has died (SAF, question 2);
- b) If the field center learns of a participant's death outside of a scheduled interview (e.g., an obituary, surveillance staff, NDI or if the death is reported to ARIC by a next of kin).

In the latter instance (b), the research staff opens a DEC form under this participant's ID and enters as much information as is available from the obituary or other source about the date (question 2) and place of death (question 3). Then allow at least three months to elapse, to allow the family time to grieve, before scheduling an interview with the proxy respondent. Administer the remainder of the DEC. If the participant is 'no more contact' (ICT1=0), do not call the proxy and go directly to question 13 and answer (a) Complete. This action applies to all deaths identified outside of an interview, regardless of the scheduling window (AFU or SAF) during which the death occurred, was identified, or the follow-up interview is made. A DEC form pending resolution may trigger automatic queries from the ARIC CC; these should be considered reminders to assist in managing such pending interviews.

When the follow-up call is made to the proxy respondent, determine the type of scheduling window (AFU or SAFU) during which the interview occurs because the death needs to be documented with either the AFU or SAF form. If this interview falls during the AFU window, complete the AFU form. If this interview falls during the SAFU window, complete the SAF form.

### II. Detailed Instructions for Each Item

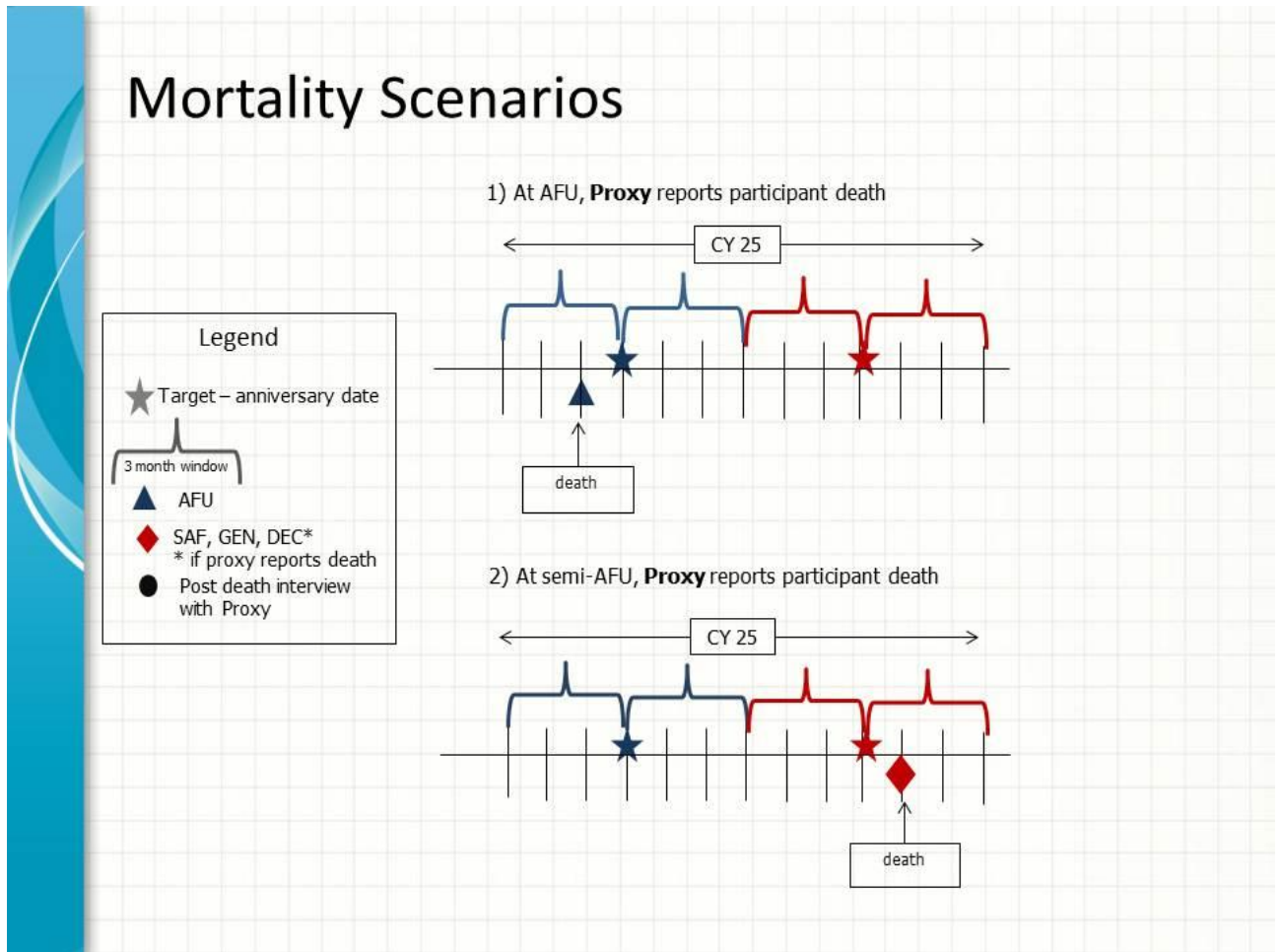
- 0a. Enter the date this form is last updated in the DMS.
- 0b. Enter the ID of the ARIC staff person who last updates this form.

#### **-- For deaths identified outside of a scheduled interview --**

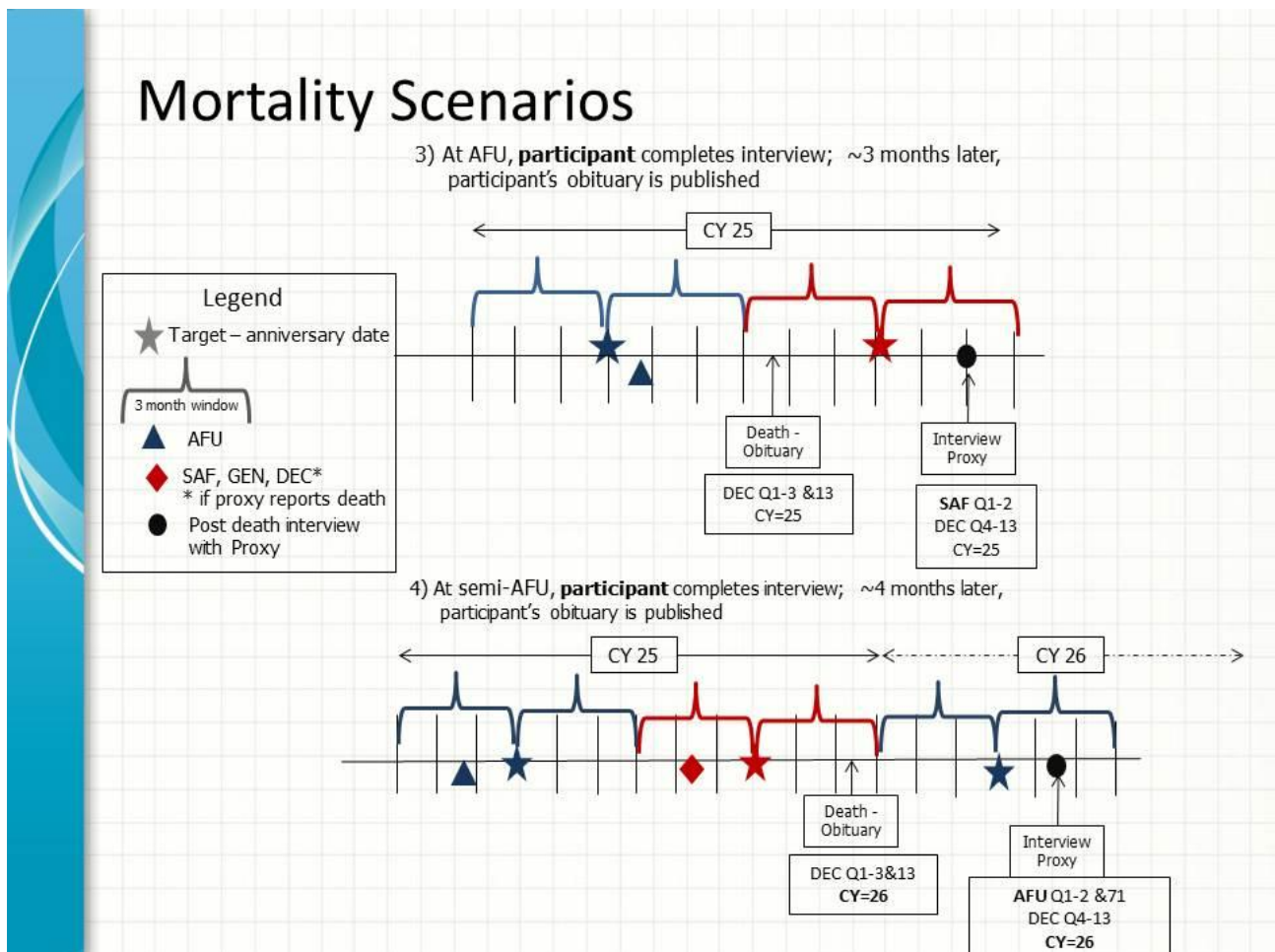
Complete questions 1-3 as instructed below and 13. (The hospitalization information (questions 6-12) is collected from the proxy three months or longer after the death occurred, only if the participant was not 'no more contact' (ICT1=0).)

## Participant Death Mortality Scenarios

1. At AFU, **Proxy** reports participant death
  - Complete AFU Section A. STATUS, Section B. DEATH INFORMATION [CLOSURE SCRIPT] & Section H. ADMINISTRATIVE INFORMATION.
2. At semi-AFU, **Proxy** reports participant death
  - Complete **SAF** Section A. STATUS, Section E. ADMINISTRATIVE INFORMATION & **DEC**



3. At AFU, **participant** completes interview; a while later, participant's obituary is published
  - Complete **DEC** Section A. DEATH INFORMATION Q1-3 & Section E. ADMINISTRATIVE INFORMATION Q13 (select "b").
  - When the proxy is interviewed about the death, complete **SAF** Section A. STATUS, Section E. ADMINISTRATIVE INFORMATION & remainder of **DEC**. Change DEC Q13 to "a". Make the date of **DEC** Q0a. Completion Date the same as the **SAF** Q0a. Completion Date.
  
4. At semi-AFU, **participant** completes interview; a while later, participant's obituary is published
  - Complete **DEC** Section A. DEATH INFORMATION Q1-3 & Section E. ADMINISTRATIVE INFORMATION Q13 (select "b").
  - When proxy is interviewed about the death, complete **AFU** Section A. STATUS Q1-2 & Section H. ADMINISTRATIVE INFORMATION. Continue with DEC Q4-12 and change DEC Q13 to "a". Make the date of **DEC** Q0a. Completion Date the same as the **AFU** Q0a. Completion Date.



**-- For interviews with the participant's proxy or contact --**

When the interviewer makes contact with someone on the telephone (may or may not be the follow-up proxy), read the following script.

**Script: "Hello, this is (YOUR NAME) from the ARIC Study. May I please speak with (NAME OF CONTACT)?"**

If the follow-up proxy ("respondent") is available, greet them with the following script.

**Script: "Hello [name of respondent]. My name is [your name] and I am from the ARIC Study. We were saddened to learn of [participant's name] death. Please accept our condolences for your loss. Would you be willing to answer a few questions about [participant's name]?"**

**A. DEATH INFORMATION**

1. Record the source of the information about the participant's death.
2. Record the exact date of death according to the informant, obituary or other documentation. If the reported date of death differs according to different sources, chose the one deemed most reliable. If the exact date of death is unknown, record the month and year. If a partial date of death cannot be ascertained whatsoever, record the date on which the death became known to the ARIC Field Center
3. Location of death: Attempt to secure the date and location (city/county, state) of death. Note, this information may be provided in the obituary. Take steps to begin a death investigation by initiating a Cohort Event Eligibility Form. Obtain as much information as possible from the informant. If the state is known, but not the city/county, record as much information as is available.
4. Determine whether the respondent is able to answer questions about hospitalizations prior to the participant's death. If the respondent is unable to answer these questions, try to identify another contact person who might be able to provide this information. Go to Section E. ADMINISTRATIVE INFORMATION item 13 and code as 'Partially complete - interruptions' and obtain contact information for the person.

Ensure the information is in the CIU and read closure script

**B. HOSPITALIZATION FOR HEART ATTACK/CONDITION/STROKE**

6. Indicate whether the participant was hospitalized for a heart attack, or heart condition, or stroke since the previous contact AFU interview. Frequently, a patient is admitted for heart attack but discharged with a diagnosis other than a heart attack, such as tachycardia (uneven heart rate) or esophageal reflux (indigestion).
- 6a-7b. Select hospital from drop down list. If the hospital is not on the drop down list, enter the hospital name. Enter the admission date in month/year format (specific day is not needed). Complete items 7a-7b for a second hospitalization.

**C. OTHER HOSPITALIZATIONS**

8. This question asks the proxy/informant to recall whether the participant had any **overnight** hospitalizations or overnight observation stays in a hospital for any other reason since

his/her last contact. This includes observation stays in a hospital, but interviewers should not probe whether these were inpatient or outpatient admissions.

If there was a positive response to overnight hospitalizations or observation for any reason, read the following script:

**“For each time he/she was admitted overnight as a patient in a hospital, I would like to obtain the reason he/she was admitted, the name and location (city, state) of the hospital, and the date.” When was the first time he/she was hospitalized since our last contact with him/her on (mm/yyyy) (date of last contact)??**

This does NOT include overnight admissions to nursing facilities and/or rehabilitation centers, and does NOT include being seen in an emergency room or urgent care facility for outpatient treatment and sent home. These types of visits are recorded in items 14-16b.

Use neutral probes to elicit all hospitalizations. For the (first) overnight stay, record the reason for the hospitalization, the hospital name, city, and state, and the discharge date (month and year) of the hospitalization. Probe for additional hospitalizations.

8a-10c. Record information on all hospitalizations reported since the time of last contact. There is space to complete 3 hospitalizations. If there are more than 3, enter the 3 most relevant to ARIC (e.g., those related to cardiovascular disease). Select hospital from drop down list. If the hospital is not on the drop down list, enter the hospital name. Enter the admission date in month/year format (specific day is not needed).

Starting in Nov 2020, priority is given for reporting COVID-19 hospitalization to the surveillance/abstractor staff at your field center. If the reason for hospitalization is COVID-19 related, please relay this information on to abstractor staff, using existing field center procedures, but in an expedited fashion. At a minimum, the CEL (including ICD-10 codes) should be entered in CDART as soon as possible.

#### **D. OUTPATIENT TREATMENT**

11-12. The intent of these two questions, in sequence, is to capture visits of the deceased participants to an emergency room or medical facility for outpatient treatment related to difficulty breathing or a heart problem. This could include outpatient treatment of angina, blood clots, heart failure, or angioplasty.

These two questions are specifically trying to identify any OTHER cardiovascular events or procedures that may have occurred in the outpatient setting. If the informant answers ‘yes’ to both #14 and #15, then answer items 16a, 16a1 and 16b. Otherwise, the form skips to item 71.

12a-12b. These questions ask the proxy/informant to recall emergency room visits or other medical facility visits of the deceased participants for outpatient treatments related to difficulty breathing or heart problems. Collect and record the date of this visit. Remind the informant that this is the participant’s most recent visit to an emergency room or outpatient medical facility for the heart problem or difficulty breathing. Select the ER or medical facility name from drop down list. If the facility is not on the drop down list, enter the name. Enter the visit date in month/year format (specific day is not needed). Although the name of the facility and the date of visit are recorded, a release of protected health information is not requested.

**CLOSURE SCRIPT:**

**"Thank you very much for answering these questions."**

**E. ADMINISTRATIVE INFORMATION**

13. Death information completion status. Enter the code that describes whether or not the SAF death information was completed.
- A. Complete: Direct contact was made and the proxy respondent provided all the questionnaire information he or she could offer. The contact is not required to answer every questionnaire item to have completed the interview.
  - B. Partially complete, contact again within window (interruptions): This could be due to i) direct contact was made, but the questionnaire could not be fully for reasons other than a refusal, or ii) death was found out via surveillance or other means, and interview with participant's proxy or contact is pending. This status is not a final status, as i) the interviewer will be attempting another contact to continue the interview, or ii) the interviewer will be contacting the participant's proxy or contact for the first time to complete the form. The final Death Information Completion Status for the given time frame must be a. Complete, or c. Partially complete; unable to complete within window (done).
  - C. Partially complete, unable to complete within window (done): Either i) direct contact was made, but the questionnaire could not be fully administered in the given time frame, or ii) the participant's proxy or contact could not be contacted and interviewed within the window.