

Appendix E

Katrina and Rita Exposures Registry Pilot Screener

Form Approved

OMB No. 0923-XXXX

Expiration Date: XX/XX/20XX

Public Reporting Burden Statement

Public reporting burden of this collection of information is estimated to average 2 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to CDC/ATSDR Information Collection Review Office, 1600 Clifton Road, NE, MS D-74, Atlanta, Georgia 30333; ATTN: PRA (0923-XXXX).

KARE Registry Intro, Screening, and Proxy Scripts

A. Intro/Screening

INTRO1.

Hello, this is _____ calling on behalf of the Agency for Toxic Substances and Disease Registry (ATSDR), a federal health agency in the U.S. Department of Health and Human Services. Can I speak to {fill (insert name)}?

[INTERVIEWER: IF ASKED WHY, SAY: We recently sent them a letter and are calling to invite them to participate in the Katrina and Rita Exposures Registry.]

[INTERVIEWER: IF PERSON UNAVAILABLE PROBE AS TO WHY TO DETERMINE IF A CALLBACK VS A PROXY IS NEEDED.]

[IF A PROXY NEEDED, SAY: "Can I speak to the person who is best able to answer questions on behalf of {fill (insert name)}"]

- 1 Named person is available (Go to Intro2)
- 2 Proxy needed (e.g. minor, deceased, mentally incompetent, institutionalized, incarcerated) (Go to P0)

INTRO2.

[INTERVIEWER - READ IF NECESSARY: Hello, this is _____ calling on behalf of the Agency for Toxic Substances and Disease Registry (ATSDR), a federal health agency in the U.S. Department of Health and Human Services.]

I am calling to invite you to participate in the Katrina and Rita Exposures Registry. ATSDR is developing a registry of people who stayed in FEMA-supplied trailers after Hurricanes Katrina and Rita. We recently sent you a letter about this Registry. I would like to ask you a few questions to see if you are eligible to participate. Also, I want to let you know that this call may be monitored or recorded for quality purposes.

[INTERVIEWER: IF SAMPLE MEMBER MENTIONS THAT THEY DIDN'T RECEIVE THE LETTER, SEE IF THEY WILL CONTINUE ANYWAY WITHOUT IT]

- 1 Continue (Go to S1)
- 2 Would like copy of letter (Go to Remail)

S1. Are you 18 years of age or older?

- 1 Yes (Go to MC1)
- 2 No (Go to P0)
- 8 DON'T KNOW (Go to P0)
- 9 REFUSED (Go to P0)

Programming note: Launch to Blaise for MC1. Questions P0 thru P3 program in CATI-CMS.

MC1. How did you hear about the Katrina and Rita Exposures Registry?

[INTERVIEWER: DO NOT READ LIST. CODE ALL THAT APPLY]

1. NEWSPAPER
2. FLYER
3. WEBSITE
4. RADIO
5. FACEBOOK
6. TELEVISION
7. BILLBOARD
8. POSTER
9. RELATIVE/FRIEND
10. COWORKER
11. COMMUNITY MEETING
12. EMPLOYER
13. PHONE CALL FROM RTI (INCLUDES ANSWERING MACHINE REFERENCES)
14. LETTER
15. OTHER (SPECIFY) {max 60 characters}
98. DON'T KNOW
99. REFUSED

[IF MC1=1, 2, 3, 4, 5, 6, 7, or 8 GO TO MC2; ELSE GO TO S_GENDER]

MC2. What was the most memorable feature of the item(s) you heard or saw?

[INTERVIEWER: ENTER COMMENTS. READ THEM BACK TO THE RESPONDENT TO VERIFY THEY ARE CORRECT BEFORE MOVING TO THE NEXT QUESTION.]

{allow 500 characters}

S_GENDER. For survey purposes, I need to confirm if {fill: you are} {if proxy fill: (insert name) is} male or female?

- 1 MALE
- 2 FEMALE
- 8 DON'T KNOW
- 9 REFUSED

S2. We have {fill: your} {if proxy fill: (insert name)'s} primary home address before Hurricanes Katrina or Rita as:

[LOAD PRELOAD INFORMATION:

damage_street

damage_city, Damage_state Damage_zip]

Is this correct?

[INTERVIEWER: IF NO, PLEASE SAY: "This is not the correct primary home address BEFORE Hurricanes Katrina or Rita?"]

[INTERVIEWER: IF DON'T KNOW ASK IF THEY CAN ASK SOMEONE OR IF THEY CAN WRITE DOWN THE ADDRESS WE GAVE AND CHECK AND CALL US BACK]

- 1 Yes (Go to S3)
- 2 No (Go to S2a_Street)
- 8 DON'T KNOW (Go to S3)
- 9 REFUSED (Go to S3)

S2a_Street. Please tell me {fill: your} {if proxy fill: (insert name)'s} primary home address before Hurricanes Katrina or Rita.

[INTERVIEWER: PLEASE READ INFORMATION COLLECTED BACK TO RESPONDENT TO VERIFY INFORMATION IS CORRECT.]

ENTER STREET ADDRESS

S2a_City. (Please tell me {fill: your} {if proxy fill: (insert name)'s} primary home address before Hurricanes Katrina or Rita.)

[INTERVIEWER: PLEASE READ INFORMATION COLLECTED BACK TO RESPONDENT TO VERIFY INFORMATION IS CORRECT.]

ENTER CITY

S2a_State. (Please tell me {fill: your} {if proxy fill: (insert name)'s} primary home address before Hurricanes Katrina or Rita.)

[INTERVIEWER: PLEASE READ INFORMATION COLLECTED BACK TO RESPONDENT TO VERIFY INFORMATION IS CORRECT.]

PRESS <BACKSPACE> OR BEGIN TYPING TO SELECT THE STATE FROM THE LOOKUP TABLE

S2a_Zipcode. (Please tell me {fill: your} {if proxy fill: (insert name)'s} primary home address before Hurricanes Katrina or Rita.)

[INTERVIEWER: PLEASE READ INFORMATION COLLECTED BACK TO RESPONDENT TO VERIFY INFORMATION IS CORRECT.]

ENTER ZIP CODE

S3. {Fill: Were you} {if proxy fill: Was (insert name)} forced to evacuate from {fill: your} {if proxy fill: his/her} primary residence after Hurricanes Katrina or Rita?

- 1 Yes (Go to S4)
- 2 No (Go to S4)
- 8 Don't know/Not Sure (Go to S4)
- 9 Refused (Go to S4)

S4. After Hurricanes Katrina or Rita, did {fill: you} {if proxy fill: (insert name)} ever live in a FEMA-supplied trailer for at least 7 consecutive days?

- 1 Yes (Go to Consent1) (If P1=3 (deceased) go to SConsent1a)
- 2 No (Go to Ineligible)
- 8 Don't know/Not sure (Go to Ineligible)
- 9 Refused (Go to Ineligible)

SConsent1. Based on your responses, {fill: you are} {if proxy fill: (insert name) is} eligible to enroll in the Katrina and Rita Exposures Registry.

The survey will take approximately 20 minutes. The purpose of this Registry is to see if enough eligible people who lived in FEMA supplied trailers can be found and if they are willing to participate. We will ask you some questions about when {fill: you} {if proxy fill: (insert name)} lived in the trailers. We will also ask you about other people who might have lived in the trailer and may contact them or you in the future for more information.

All of your answers will be kept private. Answering these questions is voluntary, but important. You can skip any question or stop the survey at any time. If you choose not to participate, {fill: you} {if proxy fill: (insert name)} will not lose any benefits or services that {fill: you} {if proxy fill: he/she} may be receiving from any government agency.

- 1 CONTINUE (GO TO CONSENT2)

SConsent1a. Based on your responses, {if proxy fill: (insert name) is} eligible to enroll in the Katrina and Rita Exposures Registry.

The survey will take approximately 5 minutes. We will ask you some background questions about {if proxy fill: (insert name)}. All of your answers will be kept private. Answering these questions is voluntary, but important. You can skip any question or stop the survey at any time.

- 1 CONTINUE (GO TO CONSENT2)

SConsent2. It is possible that some of the questions I ask might make you remember what happened after Hurricane Katrina or Rita and may upset you. You can stop or take a break at any time. There are no benefits to you from participating in this survey, but the success of this Registry may allow us to create a larger Registry where many more people can be enrolled.

If you have any questions or concerns about participating in the Registry, you can call Suzanne Triplett at 1-800-XXX-XXXX. If you have any questions about your rights as a research participant, please contact RTI's Office of Research Protection toll-free at 1-866-214-2043. You can also contact CDC's Human Research Protection Office at 1-800-232-4636.

Do you have any questions before we get started?

1 CONTINUE (IF P1=3 (DECEASED), GO TO DECO (IN MAIN INSTRUMENT); ELSE GO TO EX0 (IN MAIN INSTRUMENT))

B. Proxy

P0. [INTERVIEWER: IF PERSON INDICATED THEY ARE A MINOR, ASK TO SPEAK TO SOMONE OVER 18. IF SOMEONE OVER 18 COMES TO THE PHONE, READ INFO BELOW. IF CAN'T GET SOMEONE OLDER THAN 18, BREAKOFF AND SET CALLBACK]

[INTERVIEWER - READ IF NECESSARY: Hello, this is _____ calling on behalf of the Agency for Toxic Substances and Disease Registry (ATSDR), a federal health agency in the U.S. Department of Health and Human Services. I was told that you are the person who is best able to answer questions on behalf of {fill (insert name)}.]

1 Continue (Go to P0a)

P0a. I am calling to invite you to participate in the Katrina and Rita Exposures Registry on behalf of {fill (insert name)}. ATSDR is developing a registry of people who stayed in FEMA-supplied trailers after Hurricanes Katrina and Rita. We recently sent {fill (insert name)} a letter about this Registry. I would like to ask you a few questions to see if you are eligible to participate on behalf of {fill (insert name)}.

Also, I want to let you know that this call may be monitored or recorded for quality purposes.

1 Continue (Go to P1)

2 Would like to receive copy of letter (Go to Remail)

P1. WHY IS A PROXY BEING INTERVIEWED?

[INTERVIEWER- IF NECESSARY SAY: I just need to confirm the reason {fill (insert name)} is not capable of completing the interview right now.]

- 1 SERIOUSLY PHYSICALLY DISABLED, BUT MENTALLY COMPETENT
- 2 MENTALLY INCOMPETENT
- 3 DECEASED
- 4 INSTITUTIONALIZED
- 5 INCARCERATED
- 6 UNDER 18
- 7 OTHER

P2. What is/was your relationship to {fill (insert name)}?

- 1 Spouse
- 2 Mother
- 3 Father
- 4 Daughter/Son
- 5 Sister/Brother
- 6 Grandparent
- 7 Other Blood Relative
- 8 Mother/Father In-Law
- 9 Other In-Law
- 10 Friend
- 11 OTHER

P3. In case we get disconnected and I need to call you back, can you please give me your name?

{allow 60 characters}

[INTERVIEWER: IF PERSON IS VERY HESITANT TO PROVIDE THEIR NAME, SAY: "Your initials will be fine."}]

[GO TO S1]

C. Other Scripts

Sineligible. We sincerely appreciate your willingness to talk with us about the Katrina and Rita Exposures Registry. Today we are only looking to talk with those that were forced to evacuate their primary residence due to the hurricanes and who lived in a FEMA supplied trailer for at least 7 consecutive days. Thank you very much for participating today. Have a good day/evening.

Remail. What name and address should we use to mail you a letter about the Registry?
Enter First/Last Name, Address, City, State, Zip

Refusal. Hello, this is _____ calling on behalf of the Agency for Toxic Substances and Disease Registry (ATSDR), a federal health agency in the U.S. Department of Health and Human Services. Can I speak to {fill (insert name)} {if proxy (fill: P3 answer)}?

[INTERVIEWER: IF PERSON NOT ALREADY ON PHONE, REREAD PARAGRAPH ABOVE BEFORE CONTINUING BELOW.]

My supervisor asked me to follow-up with you concerning a call you received from one of our interviewers about a week ago. I understand that you may have some concerns about the Registry that I might be able to address?

[Go to last unanswered question]

Voicemail. Hello, I'm calling on behalf of the Agency for Toxic Substances and Disease Registry, a federal health agency in the U.S. Department of Health and Human Services. We are trying to reach {fill (insert name)} who may have recently received information regarding the Katrina and Rita Exposures Registry. Please ask {fill (insert name)} to call 1-800-XXX-XXXX to enroll in the registry. Thank you.

Callin1. Hello. Thank you for calling the Katrina and Rita Exposures Registry. My name is _____. May I please have your name or address so that I can see if you are in our database of people to contact?

- 1 Continue (Go to last unanswered question or Intro2)
- 2 Not in database (Go to Callin2)

Programming note: Launch to Blaise for Callin2

Callin2. We sincerely appreciate your willingness to talk with us about the Katrina and Rita Exposures Registry. While your name was not selected for participation in the Registry at this time, we would like to collect your contact information in the event that we conduct a larger Registry of people who stayed in FEMA-supplied trailers after Hurricanes Katrina and Rita. Can you please provide your first and last name, address, and telephone number?

[INTERVIEWER: PLEASE READ INFORMATION COLLECTED BACK TO RESPONDENT TO VERIFY INFORMATION IS CORRECT.]

FIRST AND LAST NAME
STREET
CITY, STATE ZIP
PHONE NUMBER

[AFTER CALLIN2, ASK QUESTIONS MC1 AND MC2 BEFORE GOING TO CALLIN3]

Callin3. We have all your information recorded. Thank you very much for calling in today.
Have a good day/evening.