The ACE Interviewer's Training Manual: A Self Study Guide

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YOUR ROLE AS AN ACE INTERVIEWER

Welcome to Assessment of Chemical Exposures (ACE) interviewing! As an ACE interviewer, your primary responsibilities will include:

- reading and understanding this self-study manual,
- registering respondents in the Rapid Response Registry (RRR) if it is being used,
- completing the informed consent process with respondents,
- conducting a pencil and paper interview (PAPI) with respondents, and
- submitting data as specified by the Agency for Toxic Substances and Disease Registry (ATSDR).

Other responsibilities may be included in your role, depending on the composition of the particular ACE team and the chemical incident to which you are responding. Be sure to read all additional materials provided to you by ATSDR in addition to this manual.

Many factors make an interviewer successful. The best interviewers are quick, efficient, and cost-effective without sacrificing response rates or high data quality. The key is to combine your knowledge of survey protocols and procedures with your natural talents, creativity, and social skills.

Some important guidelines are:

- understanding the material in the survey;
- being convinced of the importance of the survey;
- respecting the privacy of the respondents;
- protecting the privacy of all respondent information, including all identifiable information (name, address, phone number, etc.) as well as interview responses;
- following all procedures and instructions carefully; and
- listening and responding to respondents' needs and concerns.

Other skills crucial to success are timeliness, organization, attention to detail, neatness, professionalism, and persuasiveness.

YOU AS A PROFESSIONAL INTERVIEWER

As an interviewer, you must always keep in mind that you are a professional doing a very important job. As a professional, you are expected to possess a great deal of knowledge about the survey you are conducting—its purpose, the type of sample, the questionnaire, and other matters. You must know what you are doing and why the work is being done, and be prepared to answer any question a respondent might have for you.

You must always maintain the highest ethical standards, collecting data with complete objectivity and treating all information you gather or observe during an interview with the utmost confidentiality and respect. You must convey to every respondent that you are completing the interview in an absolutely unbiased and confidential manner, without projecting any personal biases, opinions, or prejudices.

Finally, you must recognize that you are not a clinician or social worker. Never attempt to intervene in a personal situation that is beyond the scope of the interview you are conducting.

Respondents' Rights

The rights of study participants **must** be known, understood, and protected by all interviewers. These rights include:

- The right of informed consent, which refers to the legal requirement that respondents be given complete and accurate information so that they can make an informed decision about their participation in the survey. The information must be understandable and complete, and also convey that participation is a free choice.
- The right to refuse, which refers to an individual's right to decline to participate in the survey or to refuse to answer individual questions once an interview has begun. While it is helpful to know why individuals do not want to participate in a survey, those who refuse have no obligation to state a reason for their decision. Participation is always voluntary and any person's decision to refuse must be respected.
- The right of privacy, which is guaranteed by the Federal Privacy Act of 1974. This Act prohibits the release of data gathered by or for a federal agency without the written consent of the respondent except under very specific situations described in the act. Fines and penalties apply to individuals or organizations that violate this law. You can explain this to a respondent when trying to gain his or her trust.
- The right to accurate representation, which requires honesty in dealing with respondents and answering their questions about the survey. For example, you cannot tell the respondent that an interview will take only a few minutes if you know it will last about 30 minutes. You also cannot tell respondents that they must participate in the study.

The ACE Sample

You will be conducting face-to-face interviews with residents, responders, and workers in businesses in the area affected by the chemical incident. For residents, you will interview at least one adult per household. You will also collect data on any children present during the incident. Responders include hospital personnel, fire department employees, and law enforcement officers.

Depending on the size of the affected area, the ACE team could interview up to approximately 500 persons. ATSDR will provide you with the specific sample information that you need based on the incident.

Interview Materials

You will be given a number of interview materials and must have all materials on hand for each interview. The materials and their purpose are listed in Exhibit 1.

Exhibit 1: Interview Materials

Material Needed	Purpose
A supply of General Surveys	Use one General Survey for each adult or child age 13 and older that you interview.
A supply of Pet Surveys	Use a Pet Survey if the adult respondent reports having a pet or assistance animal that was in the affected area during the release. You will need to administer a separate Pet Survey for each larger pet reported. Fish in an aquarium or garden pond, a cage of small pets, or a nursing litter should be reported on a single Pet Survey form.
A supply of Child Surveys	Use one Child Survey for each child under age 13 who the respondent reports was in the affected area during the release.
A supply of supplemental forms	Use these forms when a table provided in the General or Child Survey does not provide enough space for all collected information. These are numbered according to the question number.
A laminated showcard	This will be used when referenced in the General Survey.
A supply of consent forms	Use Informed Consent forms, Child Assent/Parent Permission forms, Medical Records Consent forms, and Veterinary Records Consent forms to document that the participant has agreed to the survey and/or release of medical or veterinary records.
Rapid Response Registry (RRR) data	You may need to verify information in the RRR for some survey participants. If the RRR was used, you will be given this information prior to the data collection.

Obtaining Participation

Obtaining the trust and participation of a respondent to complete interviews requires careful preparation. Displaying confidence and being comfortable with forms and equipment will greatly increase your chances of success. However, that is not all you need to know. This chapter presents techniques handed down from experienced interviewers and survey experts for dealing with reluctant respondents: being prepared and professional, listening to what a respondent is really saying, and correctly addressing a respondent's concerns—sometimes before they have been raised.

Establish Rapport

The ability to build and maintain a rapport with a respondent is one of the most important tools of any interviewer. To achieve rapport, you should be sensitive to the respondent and his or her situation. Rapport building begins as you introduce yourself. To help avoid a respondent's disinterest in the survey, it is important to establish rapport early and maintain it throughout your contact. From the moment of the first impression through the "good bye," be aware of how you are being received. When you are alert and responsive to the respondent's reactions, you will be more successful in avoiding refusals and will be better equipped to counter respondent objections with appropriate responses.

Be businesslike, courteous, and confident. Interviewers walk the fine line between being assertive and aggressive. It is important not to become aggressive, which is abrasive and usually counterproductive. "Bullying" sample members into participating is unacceptable and unethical. On the other hand, an interviewer who is too passive will be unsuccessful. Passivity conveys lack of confidence or commitment to an action and, in turn, the survey itself. This attitude will not motivate the sample member who is neutral or disinterested in cooperating. In these cases, you must "sell" the survey by explaining its importance and addressing concerns in a forthright manner.

Overcoming Objections

Most individuals are friendly and willing to cooperate, but a few will have concerns, objections or fears. Some respondents may fear they are being judged by you. Often, what may appear to be a refusal to cooperate is, in reality, only an expression of concern or a need for more information. The following points will help reduce or eliminate refusals when making contacts:

- Be positive and optimistic. Assume most sample members will cooperate (in fact, most will). An air of apology or defeat can sometimes trigger a refusal. Do not invite refusals.
- Have a friendly, confident and positive manner.
- Listen carefully to the respondent's comments and try to determine the basis for his or her objections. Then, target your responses to those objections or concerns.
- Acknowledge the truth or accuracy in the respondents' statements then build on the statement with additional information that addresses the concern.

When you encounter a respondent who may be reluctant to participate, suggest that he/she try a few of the questions now to see how it goes. Successful interviewers have learned that once a respondent starts the interview, he or she usually finds the questions (or the interview process) interesting and is willing to complete the survey. If you are unable to overcome a respondent's objections and the person simply will not consent to the interview, then accept the refusal as courteously and graciously as possible and thank the person for his/her time. **Do not** pressure, argue, or otherwise alienate the person regardless of the circumstances. Always remember to be professional, courteous, and friendly.

Exhibit 2-1 lists ways to counter some of the most common refusals. Be aware that in some cases, a respondent will say they are refusing for one reason but based on other comments the respondent made, you feel there is an underlying or unspoken reason for the refusal.

Exhibit 2-1. Countering Refusals

Respondent Concern	Suggested Strategies
Too busy / No time	• Stress that the participant has systematically been selected to participate and cannot be replaced. Without the subject's information, researchers will not have a complete picture of the experiences of people in the area at the time of the chemical incident. • You should be flexible and find a time that is convenient to the respondent.
Don't like surveys	• Assure respondents the survey is not invasive and their privacy will be maintained—our interest is only in the total of all responses, not in individual answers. No individual respondent will be connected to any of the responses in any way. • Also stress that this is their opportunity to contribute to knowledge about how chemical incidents impact people living or working in the affected area.
Nothing in it for me / Uncooperative	• Stress the importance of knowing how chemical incidents can impact people in the area and the results can be used to better prepare for and handle future chemical incidents. • If appropriate, let them know that the state health department will be using the data gained to try to target aid to the community affected by the release.

Though refusals may be discouraging, learning to handle them professionally—and not personally—will be the most successful approach in the long run. Do not allow refusals to change your positive attitude and approach when interviewing. Even the best interviewers experience occasional refusals; it is not necessarily a reflection of your ability as an interviewer. The important thing is to learn from refusals and then begin fresh with the next case.

TIPS FOR OBTAINING PARTICIPATION

Successful interviewers develop their own style. Interact with respondents in a manner that is comfortable yet professional, bearing in mind the following tips from successful and expert interviewers.

- A **positive attitude** is crucial when interacting with respondents. You need to feel confident about yourself, thus creating a positive atmosphere. If you approach the respondent with an air of uncertainty, the respondent may minimize the importance of the survey or be more likely to say "no" when asked to participate. If you are not committed to and knowledgeable about the survey, the respondent is not likely to be interested.

- **Persistence** is key to gaining cooperation. Many times no one may be home and you will have to vary the times of day you try to make contact. If a person says they are unable to participate at that time, offer to come back in a couple of hours. These tactics leave the door open for re-contact, since they imply respect for the person's reason to not participate at this time. Note: If the respondent indicates that they do not wish to participate and do not want you to come back at a different time, move on to the next contact.

- It is very important that you **stress the privacy of the information collected** for the survey. Assure the person that answers are only reported in aggregate form and individual names are never associated with answers.

- Stress the **importance of each selected respondent**. Every respondent is critical to the overall success of the survey. Each respondent is unique; no one selected for the survey can be "replaced" by someone else.

- **Acknowledge and respect the sample member's time.** Many people today are very busy and do not have a lot of free time. Many do not wish to spend what free time they do have answering surveys. Getting the discussion focused on answering the first few questions can often lead to a full interview. Whenever possible, gearing the person to go ahead and start the interview with you can usually lead to a complete survey.

Working Safely in the Field

Ensuring your safety while you are working is extremely important, and no one is in a better position to do that than you. We want you to be successful and safe as you conduct your ACE interviews.

Perform interviews in pairs, ideally comprised of one male and one female, preferably with a local or state health department person on each interview team. Carry a cell phone and make sure to have the phone number of the individual coordinating the field work. Wear your government identification.

Safety Concerns on a Respondent's Property

At times, you may face safety concerns while on a respondent's property. The most frequent concern reported is about dogs. Always be cautious when approaching a strange dog. Even one who appears to be friendly can suddenly become agitated. If a dog or other menacing animal blocks the path between you and the respondent's door, be careful. If the dog is obviously aggressive, do not put yourself in a dangerous situation. Try to get the attention of someone living in the household and ask him or her to restrain the dog while the two of you talk.

It is possible that respondents themselves will cause you to be concerned about your safety. Although the vast majority of respondents are cooperative, there are some that are not so nice. Do not place yourself at risk for serious verbal abuse or physical assault. If anyone (the respondent or any other person in the household) becomes physically confrontational, violent, or threatens you in any way with a real or stated weapon, get away from that residence immediately.

Working Safely

Below are some general safety tips on working safely and smartly.

Area

- Be aware of the area—assess the situation and observe people. Stay alert and tuned in to your surroundings. Do not daydream. Know where you are going and walk with confidence.
- Observe the nearest business, police station, fire station or public building, and know their hours of operation.
- Put possessions in the trunk of your car before entering the area. Do not leave things visible in your car.
- If anyone asks who you are, briefly tell them who you are and what you are doing. They may pass the word along.
- Park your car in a convenient area. Move it as necessary.
- Avoid taking short cuts through dark or wooded areas. Avoid walking where there are tall hedges or shrubs.

Dress

- Do not wear jewelry.
- Do not carry a purse. Put your keys and a couple of dollars in a pocket.
- Dress business causal.
- We strongly recommend wearing flat shoes during field work.

Multi-unit Buildings

- Carry a flashlight—apartment building hallways can be dark even during the daytime. Light bulbs may be burned out or broken.
- Make noise, such as a low whistle or rattle your keys as you walk in the hallway or up a stairway. You do not want to startle or surprise anyone who might be hanging around.
- Go right to the selected apartment address and do your business—do not look interested in what people are doing in the hallway, or what other things are going on in the apartment building. Be aware, but do not concentrate on what is going on. You should acknowledge individuals with a nod, smile or brief eye contact, but go directly to the apartment—that is your task.
- When walking up stairs—look UP.

PERMISSION AND INFORMED CONSENT

Once you have gained verbal consent for participation but before you conduct any ACE interview, you must get the respondent's written consent to participate in the interview. Ask the respondent if they want to read the form or have it read to them. Parents or guardians must also give permission for child(ren) aged 13-17 to be interviewed by signing the Child Assent Form.

You must review the entire consent/assent form with the respondent, either by reading it aloud to them or answering questions for them as they read it to themselves. It is important to honestly answer any questions the respondent may have about the interview.

There are four versions of consent/assent forms. Following is a summary of the various forms:

- **Informed Consent** – This form should be signed by all respondents age 18 and older. It describes the purpose of the survey, explains the survey process, and tells them how they were chosen to participate. It also explains their rights as a respondent and discusses privacy. The respondent should sign and date the form prior to the beginning of the interview. In addition, there is a place for the respondent to sign if they consent to being contacted for a follow-up interview. If the respondent consents to be interviewed but not to be contacted a second time, the General Survey can still be administered to them.
- **Child Assent/Parent Permission** – This form should be signed by all children ages 13-17, along with their parent or guardian. In addition, there is a place for the child and the parent or guardian to sign if they consent to being contacted for a follow-up interview. If the child and the parent or guardian consents to be interviewed but not to be contacted a second time, the General Survey can still be administered to them.
- **Medical Records Consent Form** – If the respondent received medical care due to the incident, you will ask the respondent during the General Survey for permission to review their medical records. If the respondent agrees, you will need to collect their signature. If the respondent is under age 18, the parent or guardian will be asked to sign the consent form for the adolescent, and the adolescent should be notified of the intention to ask their parent or guardian to do so.
- **Veterinary Records Consent Form** – If the respondent has pets or assistance animals that were in the affected area during the release, you will ask the respondent during the Pet Survey for permission to review their pet's (or pets') veterinary records. If the respondent agrees, you will need to collect their signature. If the respondent who was with the animal is under the age of 18, the adult owner of the animal needs to be asked to sign the release form.

For those cases when multiple family members are being interviewed, it is advisable to have one session at the beginning of the survey process where the consent and assent forms are signed for the adult and their participating adolescent children taking part in the survey. Then, at the appropriate place near or at the end of the parent or guardian interview, the interviewer should ask them to sign the medical chart release(s) for the family (including adolescent children) and any pets affected by the release.

Respondents must sign and date the form in the space provided before beginning the interview. If the respondent does not write, he/she may make a mark ("X") to indicate their consent; you will fill in the date for the respondent. In the event a respondent does not agree to sign the Consent/Assent Form, he/she is not eligible to participate and you must <u>NOT</u> begin the interview.

PREPARING TO INTERVIEW

THE PAPER AND PENCIL INTERVIEW

The data you will be collecting will be recorded using a paper and pencil interview (PAPI). You will read the questions out loud to the respondent and record the respondent's answers on your paper survey questionnaire.

IMPORTANCE OF STANDARDIZED ADMINISTRATION

The most crucial element in the interviewing process is the standardized administration of the interview. To the maximum extent possible, **every** interviewer must administer **every** question to **every** respondent in **the same way**. This helps eliminate variability and interviewer bias, two factors that can seriously undermine the validity, or "credibility," of the data collected. Standardization minimizes the variability in the way you, as the interviewer, ask the questions.

Conducting all interviews using the rules outlined in this section will ensure that the entire interviewing team asks the questions in an unbiased manner.

GENERAL PAPI CONVENTIONS

The ACE questionnaire uses several different conventions that are discussed below. It is essential to become familiar with these conventions so that you can use them effectively.

- **Plain, lower case text:** Plain lowercase black text not in parentheses or underlined is mandatory and must be read aloud verbatim by the interviewer.

- **Underlined lower case text:** Underlined text is used primarily to indicate instructions for the interviewer and should not be read aloud. Make sure to read all interviewer instructions because they contain pertinent information.

- **Skip Patterns:** Some questions will be skipped, depending on an answer to a previous question. All skip patterns are included in the PAPI questionnaire within shaded gray bubbles and should be followed exactly. Skip patterns can follow either answer options or an entire question. Always make sure to read the gray bubble after the selected answer option or question to determine whether to go on to the next question printed or skip to a different question.

ASKING THE QUESTIONS

The following rules apply when asking the questions in the PAPI questionnaire:

1. **Ask the questions using the exact words written on the paper.**
   This may seem obvious, but it is key to ensuring comparability of the data

gathered from the survey. If you change the wording in a question, even slightly, the respondent's answer may change.

2. **When instructed, read response categories exactly as they appear.**
This is especially helpful if the respondent is not sure of the answer or if the respondent needs clarification on what are applicable answer choices. Refer the respondents to the appropriate showcards when directed to do so by the PAPI.

3. **Ask the questions in the exact order they appear in the questionnaire.**
You will administer the questionnaire many times and may be tempted to take "short cuts." However, in the event that you become familiar with the questionnaire and know what questions are coming up, do not ask any question out of sequence. The questions are ordered as they are for very specific reasons. The meaning of a question may change or be unclear if it is asked out of sequence, and the resulting answer from your respondent may cause you to skip some questions entirely if you do not follow the prescribed order. Make sure to always look for the skip patterns.

4. **Read the complete question and response options.**
The respondent may interrupt you and answer before hearing the complete question. When this happens, politely explain that you have to read the entire question, and then read the question again. Do not assume the premature response applies to the partially-read question.

5. **Read the questions slowly.**
As you become familiar with the questions, you may be tempted to read more quickly. However, you must remember that this is the first time the respondent has heard these questions, so you should read slowly enough to allow the respondent to understand everything you are asking. A pace of about two words per second is recommended. Give the respondent plenty of time to recall past events.

6. **Use introductory or transitional statements as they are written.**
Since the questionnaire covers a number of topics, focusing the respondent's attention on a new topic as it occurs in the sequence is often necessary. Transition statements are provided, and they must be read exactly as written. These statements often contain instructions for the respondent—time periods, circumstances to be considered, definitions, etc.

7. **Do not suggest answers to the respondent.**
As you go through the sections of the interview, you will come across questions you think you can answer based on information you heard earlier. You may be tempted to suggest answers to the respondent. Your job as an interviewer is to ask the questions and make sure the respondent understands, but not to answer for the respondent. Do not help the respondent choose a response.

8. **Read all questions to all respondents.**
   Even if you think that the respondent has previously answered a question, read the question to the respondent. Do not skip over a question because you think it may have been answered before.

9. **Do not be judgmental.**
   It is essential that you interact with respondents in a nonjudgmental manner. Regardless of what you hear, you must accept the information without judging. It is important that you accept all that you hear in a matter-of-fact manner so that the respondent continues to feel comfortable providing private information.

PROBING

Probing is a technique used to help ensure that the answers given by the respondent are as accurate and complete as possible. When probes are neutral or non-directive, they serve two purposes:

- They help the respondent understand the question, and
- They help obtain a clear response from the respondent **without suggesting answers**.

The general rules for probing include:

- Repeat the question if the respondent misunderstood or misinterpreted the question. After hearing the question the second time, the respondent likely will understand what is being asked. This is usually the best and most straight-forward method of probing. Similarly, reading the answer choices suggests to the respondent that the response needs to come from these choices.

- Repeat the answer if the response is too vague to answer the question. For example, if you ask the respondent for his/her current marital status, and he/she answers "I'm on the loose," an effective probe is, "On the loose?"

- Pause to indicate to the respondent that you need more or better information. This is a good silent probe after you have determined the respondent's response pattern.

- 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" or "Tell me more about…"

- Use clarification probes 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. Examples of clarification probes are "Can you give me an example?" or "Please give me a specific…?"

WHEN AND HOW TO PROBE

The following explains when and how to probe to obtain information that is complete, accurate, and useful to the researchers who will later analyze the data.

Respondent does not give a simple "yes" or "no"
Gives a clear answer, but not "yes" or "no"
If the respondent gives an answer to a yes or no question that is *completely* clear ("absolutely" "not at all", "never!"), enter "yes" or "no" even though the respondent did not actually say "yes" or "no." There is no need to probe in such cases.

Says "yes" or "no" and *more*
Respondents often say "yes" or "no" and then give you additional information. If the additional statement explains why but does not contradict the answer given, ignore the

additional information and enter the "yes" or "no" answer without probing.

On the other hand, if you think the additional information ***might contradict*** the "yes" or "no" answer, repeat all or part of the question or ask whether their answer means "yes" or "no" for clarification.

Unclear Responses

Unclear numeric answers

Some questions ask for a number (an age, the duration of something, etc.). If the respondent answers with "a few," "a couple" etc., then say: "Can you give me a specific number of (hours, days, etc.)?" If the respondent is unable to give you a specific number, ask for their best guess.

Gives a vague or unclear response

If the respondent seems to have understood the question, but gives a vague or unclear response such as "it depends" "Oh, Lord!" "sometimes yes, sometimes no," then gently say, "Is that a 'yes' or a 'no'?" If you are not sure the respondent understands or remembers the question, repeat the question, saying "Let me read the question again." When repeating the question, pause slightly between parts of complex phrases, and emphasize any words that will help the respondent understand (focus your emphasis on the time frame and the terms that describe frequency).

Gives an unrelated response

Sometimes respondents go off on a tangent without answering the question. Do not discuss personal issues with the respondent. Be polite. Without offending the respondent, bring the focus back to the job at hand by listening, smiling to acknowledge the respondent's words, and then repeat the question, emphasizing important words.

Misunderstandings

Does not understand the question

If the respondent tells you he or she does not understand a question, or if the answer makes no sense and indicates that the respondent did not understand, say **"Let me read the question again" (repeat the question, emphasizing key words)**. Note: The first sentence ("Let me read the question again") is optional and should be used only if you think it helps you maintain rapport with the respondent.

"DON'T KNOW" OR "REFUSED"

Respondents will sometimes provide "Don't know" or "Refused" responses. "Don't Know" and "Refused" are always possible responses for any interview question, and the correct instructions are below.

1. A respondent says "I don't know"

   When a respondent says "I don't know," it can mean one of three things:

   i. The respondent may need more time to think about the answer
   ii. He/she may be reluctant to tell you something personal

iii. He/she actually does not know the answer to the question—or is unsure of the best answer.

If a respondent says "I don't know . . . hmm . . ." and appears to need more time to think about an answer, then wait silently and expectantly for an answer. If you feel it would help, you may say "Take your time."

If you think the respondent has said "I don't know" because he/she is reluctant to tell you private information, you should put the respondent at ease by saying "Remember that we will not tell anyone what you say" or "Remember, there are no right or wrong answers."

Sometimes respondents truly do not know the answer to a question. The first time that a respondent says "I don't know" in this way, say "To the best of your knowledge . . ." On future questions, however, you may accept the "don't know" response in the interest of not alienating the respondent.

<u>Note:</u> Listen closely to respondents to be sure they are really saying that they don't know. "Oh, I don't know, probably not" could actually mean "no" to the respondent, while "I don't know; I could have" may mean "yes". Don't guess what the respondent means. Instead, say "Is that a 'yes' or 'no'?" using a pleasant tone.

If "Don't Know" or "Unsure" is an answer option and the respondent clearly does not know, then mark that option. If "Don't Know" or "Unsure" is not a printed answer option, then write "DK" or "Unsure" next to the question.

2. <u>A respondent refuses to answer a question</u>
   After repeating the assurance of privacy, allow the respondent to exercise the right "to refuse to answer any or all questions."

   If the respondent indeed refuses, write "REF" next to the question.

3. <u>A respondent does not answer a question</u>
   If the respondent does not answer, wait 10-15 seconds to give the respondent time to think. If there is still no response, say "Let me read the question again" (repeat the question emphasizing key words).

OVERALL ACE SURVEY DETAILS TO KNOW

- It is imperative that interviewers study the map prior to the first interview. You must know and understand the affected area and be able to assist respondents in determining whether they were in the affected area at the time of the incident.

- An introductory statement and closing statement will be drafted so that all interviewers can introduce themselves and describe the assessment in the same way. The introductory statement may be included as part of the consent form and the closing statement may be on the final page of the questionnaire.

- At the top of the first page, you must write in the Participant ID, the Household ID, the Interviewer ID, and the start and end time of the interview. In addition, because this is a paper and pencil interview, the Participant ID must be present on every page in case a page becomes separated from the rest of the questionnaire.

- The General Survey and the Child Survey are broken down into a set of modules, which are sets of questions that correspond to the same topic. Each module has a unique letter, which will come before the question numbers in that module. For example, Module D in the General Survey is titled "Medical Care;" the first question in that module is noted as D1. Note that the numbering of modules in the Child Survey matches the numbering in the General Survey (i.e., Module D: Medical Care in the General Survey is also Module D: Medical Care in the Child Survey). The questions in this module ask the respondent about the medical care they received, such as hospital care, care at a doctor's office, and medicine prescribed. The first page of each module has the title at the top, which will be helpful to you if skip patterns ask you to go to a certain module and to be aware of the types of questions you will be asking the respondent.

- Sometimes, ATSDR will remove a module if it does not apply to the incident that occurred. For example, Module C of the General Survey is the "Fire/Explosion" module. It asks respondents about the injuries they may have received as a result of the explosion during the chemical incident. If there was no explosion, these questions will not be applicable and will be removed. Therefore, do not be concerned if you go to a new module and you skipped from letter B to letter D. This just means that the questions in Module C were not applicable for that incident and were taken out of the survey. Additionally, the Child Survey has fewer questions (and modules) than the General Survey and is numbered to match the General Survey. Therefore, do not be concerned when you skip letters when going through the modules.

- If you are given an answer that does not quite fit into a given answer category, seek an answer that matches the available answer categories or appropriately answers the question. If the additional information seems important, record in in the margin of the paper.

- If you are given extra information that seems important to document, please use the margins to document this information. If the information corresponds with a certain question, please make sure to reference the question number in your comments.

- There are a few questions within the survey that ask the respondent to recall particular dates or timeframes. If the respondent does not remember the exact date or timeframe, collect as much information as you can about what the respondent remembers for the question and write it in the survey margins.

- Some questions will require the use of tables for recording answer information. If the given table does not allow enough room for all relevant information, you will have supplemental tables to use for the overflow. For example, the table for the Exposure Module (Question A2) of the General Survey allows you to record information for up to three places. If the respondent reports visiting more than three places in the area on the given date, you will need to record these additional places on a supplemental Exposure Module, Question A2 table.

- Some questions require you to read all of the answer choices aloud to the respondent. If this is the case, there will be instructions in the survey that tell you to do so. Unless specified, do not read answer choices aloud to the respondent.

- In some questions, there will be underlined instructions for you to read all answer choices. If this occurs, be sure NOT to read the answer choice "Don't Know" or "Unsure" aloud to the respondent.

- You will see interviewer instructions (underlined text and skip patterns in gray bubbles) throughout the questionnaire. While it is important to read all interviewer instructions, it is imperative to read the ones in the gray bubbles.

Question by Question Specifications (QxQs)

We have tried to make the ACE questionnaire as simple and easy to follow as possible. However, as with any survey, there are certain questions that require additional explanation and training. This section will discuss all such questions in the questionnaire. As you go through this section, you should follow along with a copy of the questionnaire.

QxQs of the General Survey

Overall Topics Of General Survey

- The General Survey will be administered to adults as well as children ages 13-17 who were in the affected area at the time of the incident.

- If an adult respondent reports that one or more children under the age of 13 were present in the area at the time of the incident, a Child Survey is completed for each child as instructed in Module N: Conclusion Statements of the General Survey. If more than one adult is present in the household at the time of the interview, ask which adult would be the best source of information about the child/children and interview him/her. Once you have completed a Child Survey for all children that were in the affected area during the release, you will return to Module N: Conclusion Statements and follow the instructions to complete the General Survey. The Child Survey will only be administered to the parent or guardian of that child.

- If the adult respondent reports having pets or assistance animals that were in the affected area during the incident, you will switch to the Pet Survey in Module N: Conclusion Statements of the General Survey. After completing a Pet Survey for all pets or assistance animals in the affected area during the release, you will return to Module N: Conclusion Statements and follow the instructions to complete the General Survey.

Module A: Exposure

Question A2 – This module attempts to collect a detailed account of the respondent's whereabouts after the incident occurred. You should only capture information about the time of the incident and after, not the respondent's whereabouts prior to the incident. If you run out of space in the table, be sure to use the supplemental sheet for this table and continue recording the information there.

- For this question, you will start with Location 1, the place where the respondent first entered the highlighted area or where the respondent was when the incident first occurred, whichever applies. Ask all questions in the table regarding that location, and record the answer by circling the appropriate response or recording what the respondent said. Be sure to record the answer in the row that corresponds to the question asked.
- You will see that the columns in the table allow you to capture information about multiple locations that the respondent visited in the affected area on the given date. You will ask the series of questions in the table for each location in the affected area that the respondent went during the incident.
- Note that inside a building, outside a building, and inside a car are all examples of different locations. Also if a respondent describes that they moved inside a different building or to a different outside location, these would qualify as another location in the table. If a respondent is inside a car, this would be classified as "inside".
- It is very important to read the underlined text (instructions to you) in the table. These instructions will let you know if more detail is needed, or if you should skip questions depending on the respondent's answer.

Question A3 – Only mark "yes" for this question if the respondent is leaving the area of the release, not moving around in the affected area.

Question A7 – If respondent says that they took a bath or shower, be sure to probe for whether they used soap and water or just water. Then check the appropriate boxes. If the respondent provides additional details, be sure to record them in the survey margins.

Module B: Acute Health Effects

Question B1– If the respondent does not remember when they experienced symptoms, probe for as much information as possible to establish a timeline. If they cannot remember whether they experienced any symptoms, go to the next module.

Question B2 – Depending on the type of incident and chemicals released, you will have a table listing a variety of possible symptoms. If you run out of space in the table, be sure to use the supplemental sheet for this table and continue recording the information there.

- For each symptom listed in the table, you must ask Question B2 i and then follow the instructions of whether to proceed to B2 ii and B2 iii before going on to the next symptom. So for each symptom, you will ask whether the respondent experienced the symptom within 24 hours of the release; if "yes," whether they were experiencing the symptom before the release; and if "yes," whether the symptom was worse after the release. You will need to replace [Symptom] with the actual symptom you are asking about from the table. For example, if the symptom in question is "red eyes" you would ask "Did you experience red eyes within 24 hours of the release?" You would then check the appropriate box for "yes" or "no." If the respondent said "no," you would ask about the next symptom. If the respondent said "yes," you would then ask, "Were you experiencing red eyes before the release?" You would then check the appropriate box for "yes" or "no." If the respondent said "no," you would ask about next symptom. If the respondent said "yes," you would ask, "Were your red eyes worse after the release?" After marking the respondent's answer, you will then ask about the next symptom.
    - Depending on the time frame that the ACE interviews are conducted, ATSDR may decide to include a fourth part to Question B2. It would read: "Are you still experiencing [Symptom]?" You would ask this question after B2 ii if the respondent says "no" or after B2 iii regardless of their response. It would be asked in the same manner as discussed above. Thus, if the symptom is "red eyes," you would ask the respondent "Are you still experiencing red eyes?" You would then check the appropriate box for "yes" or "no" and continue to B2 i for the next symptom.
- At the end of the table, there is a question that asks the respondent if they have any other symptoms. If the respondent says "yes," record the symptoms that the respondent experienced and ask B2 ii and then follow the instructions of whether or not to continue to B2 iii. If the respondent reports no other symptoms, continue to the next module.

Module C: Fire/Explosion

Question C2 i-ii – The instructions for these questions are similar to Question B2 of Module B: Acute Health Effects. You will need to ask Question C 2 i for each injury listed in the table, inserting the actual injury description in the question text.

- For some of the injuries, you will need to ask Question C2 ii if Question C2 i was answered "yes."
- At the end of the table, there is a question that asks the respondent if they have any other injuries. If the respondent says yes, record the injuries that the respondent experienced and ask C2 ii if it is appropriate. If the respondent reports no other injuries, continue to the next module.

Module D: Medical Care

Question D1 – This question asks if the respondent received medical care at a hospital, a doctor's office, or by an emergency medical technician (EMT) or paramedic. If the respondent received care at ANY of these three, then it should be answered as "yes." Follow-up questions will obtain more specific information.

Question D2 – This question is only asked if the respondent did not receive medical care. Ask the respondent why they did not seek medical care and then go to the next module.

Question D4 – If the respondent was provided care by an EMT or paramedic more than one time due to the release, be sure to note what happened.

Question D6 – The purpose of this question is to record the date that the respondent was admitted when they first visited the hospital due to the release. If the respondent went to the hospital for additional visits, the date that they were admitted for those visits should be recorded also. If the respondent cannot remember the exact date(s) they received care, probe for as much information as possible to develop a timeline. For example, you could ask the respondent if they remembered the day of the week or how many days after the incident that they went to the hospital.

Question D7 – If the respondent reports multiple dates for hospital visits, be sure to probe for whether they went to the same or a different hospital for each visit. If the respondent only says one hospital and they had more than one visit, follow-up with a clarifying question such as "just to clarify, you said that all of your visits were to the same hospital?"

Question D9 – If the respondent reported in Question D6 that they had more than one hospital visit due to the release, be sure to make note of what happened on the repeat visit(s) in the margins.

Question D10 – If the respondent was hospitalized but did not spend the night, "1 night" should still be recorded.

Question D12 – If the respondent was in ICU (Intensive Care Unit) but did not spend the night, "1 night" should still be recorded.

Question D13 – If the respondent was on a ventilator but not for a full night, "1 night" should still be recorded.

Question D16 – Use the table provided to collect all of the dates the respondent was provided care and the information about the doctor(s) or medical professional(s) who provided the care. Information about the care the respondent received in the hospital setting should not be included here. Be sure to probe to ensure that you have collected information about all dates and all doctors or medical professionals that a respondent visited. If the respondent cannot remember the exact date(s) they received care, probe for as much information as possible to develop a timeline.

Question D18 – If the respondent was prescribed medicine but does not know the name(s) of the medication(s), make sure to ask what the medicine is used for or collect any other useful information that will identify the medication.

Question D20 – This question will only be read to respondents age 18 and older. If the respondent appears unsure about signing the medical records consent form, discuss the form in more detail with them and answer any questions that they may have. If the respondent agrees to sign the form, either read the form to the respondent or answer any questions the respondent has as they read it to themselves. Collect the respondent's signature and continue with the survey. If the respondent refuses to sign the form, check "no" and continue with the survey.

MODULE E: OCCUPATIONAL HISTORY AND HOBBIES

Question E3– When Question E1 or E2 is answered "yes," you will then ask question E3 a-e, recording that information in the appropriate column of the given table. After asking these questions about Job 1, you will need to ask question E3 f, asking the respondent if they had any other jobs in the past year. If so, then questions E3 a-e should be asked about additional jobs and the answers recorded in the appropriate table columns. If the respondent has had more than two jobs in the past 12 months, record information about the additional job(s) on a supplemental table. If you do write on a supplemental table for additional job(s), be sure to circle "yes" in E3 f. If the chart contains all of the information you recorded, circle "no" in E3 f.

Question E7 – Record the information the respondent provides in the column labeled "Type of Chemical" of the table.

Question E8 - Record the information the respondent provides in the column labeled "Location where chemical was used" of the table.

MODULE F: MEDICAL HISTORY

Question F1– If respondent says "yes" to F1 question parts that have "Please specify" in parentheses, probe for specifics and write the information on the blank line where indicated. At the end of the table is a question that asks the respondent if they have any other medical conditions. If the respondent says "yes," record the medical condition that the respondent has and continue to the question. If the respondent reports no other medical conditions, continue to the next question.

Question F3 – If the respondent is taking medicine but does not know the name(s) of the medication(s), make sure to ask what the medicine is used for or collect any other useful information that will identify the medication.

Questions F1-F3 - Please note that these questions are asking about the time prior to the incident.

MODULE G: EMERGENCY RESPONSE

Question G1 – If the respondent says that they are not an emergency responder, check the appropriate box and proceed to the next module.

Question G2 – This question seeks to collect details about the specific tasks the respondent performed as an emergency responder.

Question G3 – This question should only be asked of firefighters, police officers, or other non-healthcare related first responders. This question refers to Showcard Side A. You should hand your laminated showcard to the respondent and have them choose the answer from the card. Make sure that the showcard is on the correct side. After checking the appropriate box and adding specifics as directed, proceed to the next module.

Question G4 – This question should only be asked of EMS responders, hospital emergency department workers, or other health care providers that aided victims of the release. This question refers to Showcard Side B. You should hand your laminated showcard to the respondent and have them choose the answer from the card. Make sure that the showcard is on the correct side.

MODULE H: COMMUNICATION

If respondent is an emergency responder, skip this module.

Question H1 – This question is for respondents aged 13-17 only. Once the adolescent answers Question H1, go to Question H3. Skip to Question H2 for adult respondents.

Question H2 – This question is for adults, age 18 and over. Skip this question for respondents aged 13-17. This question is for the purpose of collecting specific details about the types of information the respondent received about the release.

- You will ask H2 i and check only ONE box for the information the respondent received FIRST. Then, for the information the respondent received first, you will ask H2 ii. For H2 ii, write either yes, no, or DK (for don't know) in the appropriate boxes. If the respondent said they first learned about the release because of the commotion caused by the release, skip ii.
- Part H2 iii is a "Check All that Apply" question, meaning that the respondent can give multiple answers. For each type of follow-up information that the respondent provides, you will follow up with H2 iv. H2 iv will say [source] in brackets. You will need to replace [source] with the actual source of information the respondent said they received. For example, in H2 iii, if the respondent said they received follow-up information from a community meeting, you would ask H2 iv like this: "Was the follow-up information you received from the community meeting timely?" and then ask "Was it accurate?" For H2 iv, write either yes, no, or DK (for don't know) in the appropriate boxes.
- If the respondent provides a type of information that is not listed in the table, record it in the row titled "Other" and proceed as instructed above.

- If the respondent provides additional details about the information they received, record these details in the margins of the survey.

Question H3 – All respondents age 13 and older will be asked this question. Please note that this is a "Check All that Apply" question, meaning that the respondent can give multiple answers. Mark each answer category that the respondent gives and probe to make sure that you have collected all ways that the respondent could best be reached with information.

MODULE I: NEEDS

If the respondent is an emergency responder, skip this module.

Question I2 – If a respondent answers "yes" to any part of Question I1, please be sure to obtain all details you can from the respondent. Specific details are needed so that the state health department can direct aid to the community.

MODULE J: EXPOSURE OF OTHER PEOPLE PRESENT

Question J1 – Examples of individuals that could be with the respondent during the release include those individuals with the respondent at their home, at a business or other building, in the car, etc. If children are identified by the respondent, probe for the parent/guardian contact information. If the respondent identifies more than five individuals, record the information for these individuals on the back of the page or in the margins.

Question J2 – If children under the age of 13 are listed by the respondent, take note of this. You will be instructed at the end of the General Survey to administer a Child Survey for each of the children under the age of 13 that the respondent mentions if the respondent is the child's parent or guardian.

MODULE K: PETS

Question K1 and K2 – Question K1 and K2 ask the respondent if they have pets or assistance animals that were in the highlighted area of the map during the release. Examples of an assistance animal include a seeing-eye dog or K-9 partner with the police force. If pets or assistance animals are identified, take note of this. At the end of the General Survey, you will be instructed to administer a Pet Survey for each pet or assistance animal affected.

MODULE L: DEMOGRAPHIC INFORMATION

Question L2 - Please note that this is a "Check All that Apply" question, meaning that the respondent can give multiple answers.

Question L5-L9 – Please note that these questions refer to the information contained in the Rapid Response Registry (RRR). If the respondent is registered in the RRR, verify the information in the RRR with the respondent and record any needed corrections in questions L5-L9. If the respondent is not registered in the RRR, then you should ask questions L5-L9 and record all answers.

<u>MODULE M: SUPPLEMENTAL QUESTIONS</u>

This module will only be used when the state or local health department requests that event-specific questions be included.

<u>MODULE N: CONCLUSION STATEMENTS</u>

Question N2 – This question refers to the information in Module J: Exposure of Other People Present, Question J2.

- If Question J2 identified children under the age of 13 that were present in the highlighted area of the map during the release, you will then move on to the Child Survey and continue asking about all children reported as being present during the release. You will then be instructed to return to Module N of the General Survey to finish up the interview. Note that the Child Survey will only be administered to the parent of guardian of the child.
- If no children under age 13 were present, you will continue to Question N3.

Question N3 – This question refers to the information in Module K: Pets, Question K1 and K2.

- If Question K1 and K2 identified pets or assistance animals that were present in the highlighted area of the map during the release, you will then move on to the Pet Survey. After completing the Pet Survey, you will be instructed to return to Module N of the General Survey to complete the interview.
- If no pets or assistance animals were present, you will continue to the closing statement and complete the interview.
- After reading the closing statement, be sure to record the end time on the front page of the General Survey.

QxQs OF THE CHILD SURVEY

The Child Survey will be completed by the adult respondent who is the child's parent or guardian, as instructed in Module N: Conclusion Statements, Question N2 of the General Survey.

- The questions will be asked of each child under the age of 13 who were reported being in the affected area at the time of the incident. You will need to refer to Module J: Exposure of Other People Present, Question J2 of the General Survey to determine how many Child Surveys need to be administered.

- Throughout the survey, you will see [Child's name] in brackets. You will need to replace [Child's name] with the actual name the respondent tells you at the beginning of the interview.

- For additional explanations of the Child Survey modules, refer to module specific instructions for the General Survey. The titles of the Child Survey module and the corresponding General Survey module are the same. For example, Module B of the Child Survey and Module B of the General Survey are both titled "Acute Health Effects." Questions specific to the Child Survey that require additional explanation are below.

<u>CHILD SURVEY MODULE A: EXPOSURE</u>

Question A1 – If the individual who was with the child was either the respondent or someone else who has been interviewed, then skip Question A2. The child will have the same exposure as the individuals who have already been interviewed and asked the same set of questions. This question can be used to obtain the child's exposure information from someone else, who was interviewed or needs to be interviewed, if the child was not with their parent or guardian during the release.

See Module A: Exposure for additional discussion.

<u>CHILD SURVEY MODULE N: CONCLUSION STATEMENTS</u>

If there are more children, as identified in Module J: Exposure of Other People Present, Question J2, of the General Survey, you will need to complete Child Surveys for each additional child. Be sure to record the end time on the front page of the child survey before beginning to ask about next child. If there are no more children under the age of 13 to ask about, you should record the end time on the front page of the Child Survey and return to Module N: Conclusion Statements, Question N3 of the General Survey.

QXQS OF THE PET SURVEY

- The Pet Survey will be completed for those respondents reporting in Module K: Pets, Question K1 and K2 of the General Survey that they have pets or assistance animals that were in the highlighted area of the map during the release.

- Remember, you will need a Pet Survey for each larger pet reported. Examples of a larger pet include birds, dogs, cats, and large reptiles. Fish in an aquarium or garden pond, a cage of small pets, or a nursing litter should be reported on a single Pet Survey form. After completing a Pet Survey for each pet or assistance animal that was present, return the General Survey to complete the interview.

- When instructed to "read all choices to the respondent," do NOT read the "Don't Know" choice aloud.

Question 4 – This question is only asked if the pet is a dog or cat.

Question 5 – This question is only asked if the pet is a dog.

Question 12 – This purpose of this question is to collect further information from the respondent about what happened to their pet if they said "yes" to any part of Question 11 a-d.

Question 15 – Skip this question if the respondent is aged 13-17; you will need to ask the owner of the pet or assistance animal to sign this form. This question is to determine whether the respondent is willing to release the veterinary records for their pet(s). Take note of their answer because it will determine your actions after completing either Questions 17 or 18.

Question 17 and 18 – You will ask Question 17 if the respondent said "yes" to Question 16. You will ask Question 18 if the respondent said "no" to Question 16.

- After completing either Question 17 or 18, you will ask about the next pet if the respondent identified multiple pets that were present during the release in Module K: Pets, Question K2 of the General Survey.
- If there was only one pet present in the area during the release or you have asked about all pets present, you will do one of the following depending on the respondent's answer to Question 15:
    - If the respondent said "yes" to Question 15, you will ask them to sign the veterinary records release form before returning to Module N of the General Survey and complete the interview.
    - If the respondent said "no" to Question 15 or the question was skipped because the respondent was aged 13-17, you will return to Module N of the General Survey and complete the interview.