



# Data Collection Technical Assistance Brief

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## Collecting Sensitive Information And Encouraging Reluctant Respondents

In most studies of vulnerable or at-risk populations, the research team must collect sensitive information about participants to learn whether a program or intervention is working. These sensitive topics can sometimes raise concerns among team members. How can they collect these data while minimizing the privacy concerns of the participants and maximizing completion of surveys, or assessments?

This brief covers two common concerns among program and evaluation staff: collecting sensitive information from vulnerable populations and encouraging reluctant respondents to provide data. Staff can use the guidance in this brief to help plan their data collections and consult the references for further reading.

### SENSITIVE QUESTIONS

#### What are they, what are the consequences, and how can we mitigate their effects on data quality?

As part of the Regional Partnerships Grant (RPG) program, evaluators and data collectors may need to ask about sensitive topics to learn whether their program is having the desired effects (for a description of the RPG program see box on next page). For example, a key goal of the programs funded under RPG is to gather information about substance use, adult and child trauma, or child behavior problems from participants who have or are at risk of substance use disorder. Such topics may be difficult for respondents to discuss but are necessary for program staff to gauge a family's ongoing needs or for evaluators to measure the effects of an intervention.

#### 1. What are sensitive questions?

Certain topics are considered by most people to be taboo, such as drug use, sexual behaviors, voting, and income (Tourangeau and Yan 2007). Tourangeau and Yan (2007) describe three facets

of sensitive questions: intrusiveness, threat of disclosure, and social desirability.

- Intrusiveness means the respondent may see a question as an invasion of privacy, regardless of what the answer might be. Questions about income or religion often fall into this category.
- The threat of disclosure refers to participants' concerns about their answers being divulged outside the study team. In the RPG program or in programs serving similar populations, participants may worry that sensitive information, such as about substance use, will be reported to third parties such as child welfare agencies, courts, or substance use treatment providers.
- Social desirability refers to respondents providing answers that they perceive as socially unacceptable. A question may require respondents to admit they violated a social norm, which they may hesitate to do. For example, as a part of the RPG study, participants are asked to describe their own depression symptoms. They may report fewer depressive symptoms than they truly feel because of the social stigma associated with mental health problems.

**MATHEMATICA**  
Policy Research



**RPG**

Regional Partnership Grants  
and Cross-Site Evaluation

**The Regional Partnerships Grant (RPG) program supports partnerships** between child welfare agencies, substance use disorder treatment providers, and other systems to address the needs of children who are in, or at risk of, out-of-home placement due to a parent's or caretaker's substance use disorder. The grant maker is the Children's Bureau within the Administration on Children, Youth, and Families; Administration for Children and Families; U.S. Department of Health and Human Services.

The legislation that funds the partnerships requires the agencies to collect and report on a set of performance measures. It also requires partners to evaluate their programs and participate in a national cross-site evaluation (Administration for Children and Families 2012, 2014). To fulfill these requirements—and to support their own program services—partnerships collect data from the adults in their programs. For example, outreach staff might administer assessments to prospective participants, or evaluators might collect baseline and follow-up data using a variety of instruments (U.S. Department of Health and Human Services 2016; Strong et al. 2014).

Depending on each partnership's program and combination of services, participants may be in substance use disorder treatment, may have recently completed treatment, or may be at risk of substance use disorder when data are collected. Partners and their evaluators may therefore be concerned about the best way to collect high quality data from adults who are facing numerous challenges.

Social desirability is closely associated with the threat of disclosure. It can cause people to not report certain activities (such as illicit drug use) because they can have legal consequences. But it can also prevent them from providing honest answers that don't have legal ramifications but do violate a cultural or social norm.

## 2. What are the consequences of asking sensitive questions?

Sensitive questions can hurt data quality. Three common ways data quality can suffer is through overall nonresponse, item nonresponse, or inaccurate responses.<sup>1</sup>

- The overall nonresponse rate refers to the percentage of respondents who do not take part in a survey or questionnaire. Often, respondents may not complete a questionnaire if it includes sensitive questions (see Catania et al. [1990] for an example).
- The item nonresponse rate is the percentage of respondents who agree to participate in data collection but refuse to answer a certain question because it's sensitive. The most common questions affected by item nonresponse, regardless of population, are questions about income, which are seen as highly intrusive by most respondents (Juster and Smith 1997; Moore et al. 1999).

- Inaccurate responses typically arise from social desirability bias. Respondents often under-report behaviors that violate social rules and over-report those that seem more desirable (Tourangeau and Yan 2007). Respondents seem to under-report on topics such as illicit drug use (Fendrich and Vaughn 1994; Johnson and O'Malley 1997), alcohol consumption (Lemmens et al. 1992), and smoking (Patrick et al. 1994). Thus, data collected about substance use must be closely examined to ensure people don't miss out on needed services because they under-reported certain behaviors.

## 3. How can we mitigate the effects of question sensitivity?

Asking sensitive questions is a necessary part of running or evaluating a program. Program staff often use the answers participants provide as a diagnostic tool in ensuring a family or child is getting the services or attention they need. For evaluators, sensitive questions are often related to the key outcomes of interest for a program or intervention, such as a reduction in drug or alcohol use, a decrease in depression or post-traumatic stress, or an increase in the reunification of children in the child welfare system.

But regardless of the topic of the sensitive question, there are several approaches that can make data collection easier. These strategies include ensuring confidentiality and modifying the design of the survey or questionnaire.

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<sup>1</sup> Though beyond the scope of this review, a common concern about asking sensitive questions is the risk of retraumatizing research participants who have experienced violence, abuse, or other distressing events. However, two recent meta-analyses showed that asking about past traumas or violence may cause minimal distress, and people find participation in studies to be positive (Jaffe et al. 2015; McClinton Appollis et al. 2015).

be protected can go a long way toward making sure they respond—and respond honestly—to sensitive questions.

Data collectors should inform participants that the research was reviewed and approved by an institutional review board (IRB). IRBs ensure that research is conducted ethically, an appropriate process for informed consent is in place,<sup>2</sup> and data about research participants are kept confidential. Reassure participants that their personal information and responses to questions will not be revealed unless required by law.

Evaluators or study staff can also obtain a certificate of confidentiality from the National Institutes of Health if they think respondents may not answer sensitive questions due to fear of disclosure. With this certificate, researchers cannot be forced to disclose information that identifies the participant—even by a court subpoena—in any civil, criminal, administrative, legislative, or other proceedings at the federal, state, or local level.<sup>3</sup> This assurance can help alleviate the concerns of participants who may be reporting their use of illicit drugs. For more information about certificates of confidentiality, visit <https://humansubjects.nih.gov/coc/index>.

Remember that assuring participants of confidentiality does not go very far if the data collection does not occur in private. Aquilino et al. (2000) found that respondents may not answer questions about substance use truthfully if they feel they are not in a private setting.

**Modifying the survey design.** Altering the design of a survey or questionnaire, with the sensitive questions in mind, can help elicit accurate responses from participants. It may be especially effective in keeping people from

under-reporting behaviors or conditions that seem socially undesirable.

First, consider which mode of administration to use for a survey containing sensitive topics or questions: self-administered or interviewer-administered.

- *Self-administered questionnaires* can either be paper self-administered questionnaires (SAQs) or web questionnaires. Paper SAQs are print surveys filled out by the respondent. The web versions are surveys that participants can access online at a convenient time and place.
- *Interviewer-administered* modes can be either in person or by phone. In person, a data collector will usually ask the participant questions and record the answers on a paper survey or help the participant take the survey on a computer or tablet. For phone surveys, a data collector can call participants and ask them questions from a questionnaire, and then record the responses on paper or via a computer program.

Typically, respondents are more willing to report sensitive information in a self-administered survey than in an interview. In a meta-analysis, Richman et al. (1999) found that more respondents reported substance use when the questions were self-administered than when they were asked by an interviewer (see also Harrison [1997]). However, there are trade-offs between these different modes, and program and evaluation staff should decide what approach works best for their study population.

Second, place sensitive questions in the middle of the survey (Fink 2002; Makkai and Mcallister 1992). For surveys administered by an interviewer, putting these questions near the middle allows the interviewer to draw the respondent into the discussion and build trust and rapport before sensitive topics are raised. For SAQs, this strategy elicits similar results. It gives respondents a “warm-up” period and allows them to get into the heart of the survey before delving into more sensitive questions. Question placement, regardless of mode of administration, also leaves room to pose easy or less-sensitive questions at the end of the questionnaire, allowing respondents to end the survey on a more positive or neutral note.

Finally, use language that normalizes a behavior. Normalizing language typically precedes a question and describes the behavior as common

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<sup>2</sup> Obtaining voluntary informed consent is a legal requirement for all federally funded research involving human subjects. Informed consent means the researcher discloses appropriate information to a potential research participant so that he or she can decide whether to take part in the study. A consent form explains the nature of the potential participant's involvement in the study and ensures that his or her rights are explained and respected. The form also describes the potential risks and benefits of participation and provides the option of declining to participate. More information can be found at <http://www.hhs.gov/ohrp/regulations-and-policy/guidance/faq/informed-consent/index.html>.

<sup>3</sup> A certificate of confidentiality does not prevent researchers from voluntarily disclosing information about incidents such as child abuse or intent to hurt oneself or others.

among other study participants. For example, in a study of marijuana use among men, a researcher could say, “Most men ages 18 to 35 report having tried marijuana at least once” and then ask the respondent about his own marijuana use. Or in a study of young mothers, the researcher could ask, “Even the calmest parents get angry at their children sometimes. Did your children do anything in the past seven days to make you angry?” Although this strategy has been shown to significantly increase item response rates and produce more accurate responses (Fowler 1995), not all studies have shown it to be effective (Ong and Weiss 2000).

## ENCOURAGING RELUCTANT RESPONDENTS

### Gaining cooperation and interpreting and avoiding refusals

Key to obtaining high quality data is gaining cooperation and avoiding refusals from potential respondents or program enrollees. Encouraging reluctant respondents goes hand in hand with collecting sensitive information because respondents may not want to answer sensitive questions. Thus, at the outset of program or study enrollment, program and evaluation staff should consider how to engage participants.

#### 1. Gaining cooperation

Data collectors, program staff, and evaluators can use the following strategies to gain the cooperation of participants:

- Approach participants in a friendly, non-threatening way. Although data collectors should always dress and act professionally when discussing the program or evaluation with participants, they should never sound condescending.
- Avoid acronyms, or use them along with the full name, because most participants will not know the acronyms.
- Let respondents know upfront who is contacting them and why. Respondents will appreciate being approached in a straightforward and professional manner.
- Ensure that data collectors have access to materials such as the study or program brochure, a toll-free number participants can call for more information, and advance letters.

Advance letters are provided to participants before the data collection and describe the study or program, the incentives, and the data collection efforts the person is being asked to take part in.

- Know how to answer questions about the study; describe the purpose of the study or evaluation; and give the name of the agency, grantee, or organization conducting the data collection. Create a frequently asked questions document to anticipate participants’ questions and provide consistent responses.
- Tell participants that they are important to the study and that, without them, the study team cannot obtain high quality data. Participants should know that their time and efforts are valued.
- Inform participants that their participation is voluntary and that they can skip any question they are not comfortable answering.

#### 2. Interpreting Refusals

Data collectors should listen carefully for soft versus hard refusals. A hard refusal is when a person definitively asks not to be contacted again—in which case, the study team should stop all contact.

A soft refusal is when, for example, a participant does not return messages or continually says he or she is not available for data collection appointments—but does not definitively refuse. With soft refusals, the study team can approach the person again at a more convenient time or have a different member of the team make contact. Data collectors should be trained to disengage with families before a soft refusal becomes a hard refusal to leave the door open for a possible conversion to “yes” later. However, seven or eight soft refusals are typically a sign that the person will not participate.

#### 3. Avoiding Refusals

To avoid refusals, data collectors and other team members should be trained to use active listening, diagnose barriers to participation, and address respondents’ concerns about taking part in a study or follow-up data collection.

- **Use active listening.** Data collectors should give their full attention to the person speaking and suspend their own judgments to comprehend what the speaker is saying.

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- **Diagnose the barrier.** Key to avoiding refusals or converting a soft refusal into a “yes” is diagnosing the barrier to participation. To do this, the data collector must be able to interpret what the person is saying (even when it requires reading between the lines), identify the underlying barrier, and respond to it.
- **Address the participant’s concerns directly.** Once the data collectors have diagnosed the barrier to participation, they must honestly address all of the participant’s concerns. They should not mislead him or her (for example, by understating how much time the data collection appointments will last). Once the data collectors have addressed the concerns with clear, concise, and factual answers, they should help the participant think of ways to overcome the barriers (Table 1).

**Table 1. Participant concerns, barriers, and ways to overcome barriers**

Common participant concerns	Barrier being described	Ways to address barrier
<b>“I work full time.”</b>	Perceived burden of study	<ul style="list-style-type: none"> <li>• Reinforce actual time study will take</li> <li>• Offer to collect the data in sessions</li> <li>• Remind them of incentives to compensate them for their time</li> </ul>
<b>“I’ve never heard of your program/ organization/ study.”</b>	Legitimacy of study	<ul style="list-style-type: none"> <li>• Identify yourself again, your affiliation, the purpose of the study, and the name of the organization conducting the study</li> <li>• Affirm that you are not trying to sell them anything or collect money (or mention that you will pay them)</li> <li>• Provide a website where they can learn more about the program or study, if available</li> <li>• Offer to provide the phone number of the agency, program, or project director who can vouch for the study</li> </ul>
<b>“I don’t have time for this right now.”</b>	Bad timing/ respondent in a hurry	<ul style="list-style-type: none"> <li>• Identify a better time to call back</li> <li>• Set up an appointment to call them back</li> <li>• Leave your name and number and tell them you can be reached anytime</li> </ul>
<b>“I don’t want anyone in my business.”</b>	Confidentiality concerns	<ul style="list-style-type: none"> <li>• Assure them the study is confidential, and their responses will be anonymous</li> <li>• Tell them about the certificate of confidentiality, if applicable</li> <li>• Let them know the study is voluntary, and they can leave the study anytime</li> </ul>
<b>“No one cares what I have to say.”</b>	Response is not needed for study	<ul style="list-style-type: none"> <li>• Describe why the information is important</li> <li>• Emphasize any benefits—to children or to other people like themselves—in learning if a program works</li> <li>• Convey the importance of the information even if the participants are no longer in the program</li> </ul>
<b>“I don’t know that I can answer all the questions correctly.”</b>	Hesitant about content of survey or sensitivity of questions	<ul style="list-style-type: none"> <li>• Explain that there are no right or wrong answers</li> <li>• Tell them they can start the survey and see how it goes</li> <li>• Remind them they can stop at any point, and they don’t have to answer anything they don’t want to</li> </ul>

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