

**Cognitive Evaluation of Pregnancy Risk Assessment Monitoring System
Call-Back Questions on Neo-Natal and Post-Natal Experiences with the Healthcare System, Infant
Development, the Use of Various Substances, and Treatment Programs**

Stephanie Willson
National Center for Health Statistics

Dánae Corado and Erika Martinez Picazo
Research Support Services, Inc.

Amanda Titus
Swan Solutions, Inc.

Introduction

The Pregnancy Risk Assessment Monitoring System (PRAMS) is a surveillance system which collects data on current public health guidelines and topical issues concerning maternal and child health.¹ Although PRAMS is primarily a paper-and-pencil self-administered survey, a subset of call-back telephone-administered questions is also planned for use. These include new questions on neo-natal and post-natal experiences with the healthcare system, infant development, mothers' use of various substances, and experience with treatment or counseling programs. The questions required a cognitive interview evaluation to understand the constructs measured by each. The call-back questions were cognitively tested by The Coordinating Center for Question Design and Evaluation Research (CCQDER) at the National Center for Health Statistics, in collaboration with the Division of Reproductive Health, National Center for Chronic Disease Prevention and Health Promotion. Findings from the cognitive evaluation assist in both question design and understandings of the survey data.

Methodology

The aim of this study was fourfold. The goals were to 1) explore the ways in which respondents interpreted the call-back questions, 2) understand how they formulated answers based on those interpretations, 3) draw conclusions about the concepts measured in each question and 4) describe how each question functions and performs in the context of the purposive sample drawn for this study. All questions were explored, but particular attention was paid to respondents' understandings of various substances (prescription pain relievers, non-prescription drugs, alcohol, and tobacco products) and treatment and counseling programs. Additional attention was paid to the extent to which questions associated with potentially sensitive topics may have caused respondents to answer in socially desirable ways.

A total of 34 cognitive interviews were conducted with mothers age 18 and over. Eighteen were conducted in English and 16 in Spanish². Priority for inclusion in the study was given to mothers who had an infant between the ages of two and 18 months. However, because of significant recruitment challenges (described below), selection was expanded (as necessary) to include mothers with children of any age (with priority given to those with children under 24 months old).

Interviews conducted in English were held in the lab at CCQDER and at a substance abuse treatment center for women with children; those in Spanish were conducted in the Chicago area in respondents' homes, libraries or

¹ See <https://www.cdc.gov/prams/index.htm> for a full description of the PRAMS surveillance project.

² The instrument in Spanish may be found in the Appendix.

coffee shops, and a local Women, Infants, and Children (WIC) office. Interviews were no longer than one hour in length. Most interviews (24) were conducted using the phone version of the instrument (see Table 1). Interviewers read each question to the respondent, recorded her answer, and then followed up with in-depth probing to explore the question-response process. Ten interviews were conducted as self-administered. In these cases, interviewers first allowed respondents to complete the questionnaire on paper then followed up with in-depth probing.

Recruitment challenges: Previous recruitment efforts in related PRAMS cognitive evaluation studies were inordinately difficult and the same was true in this study.³ Recruitment was challenging for both English- and Spanish-speaking populations. Each is discussed separately.

English-speaking respondents were initially recruited through newspaper advertisements, craigslist posts, the CCQDER respondent access database, and community outreach. In previous PRAMS studies, associating substance use with pregnancy tended to elicit negative responses from mothers who felt judged about such behaviors. This negatively affected women's willingness to participate. Hence for this study, the advertisement and screener were developed to emphasize the post-natal timeframe of the questions – substance use after (not during or prior to) pregnancy. Mothers who had Cesarean sections or early deliveries were also targeted, as they may have had a higher likelihood of the need for prescription pain relievers, without the use of these medications being the specific criteria for responding to the advertisement.

Despite these efforts to disassociate the use of substances and pregnancy, there was still a lack of response using the traditional methods of recruitment (newspaper advertisements and craigslist posts). To compensate for the lack of willing participants, age of the child was expanded to include mothers of children older than 18 months and use of prescription pain relievers, non-prescription drugs, alcohol, and tobacco products was eliminated from recruitment materials.

Successful recruitment was achieved primarily through the CCQDER respondent access database and community outreach through field recruitment. Field work was done to locate and build relationships with organizations in the region that provide services to new mothers, particularly mothers in drug treatment programs. It took a significant amount of time to locate organizations that were willing to provide access to this community. Months of explaining the study, building trust, and establishing coordination went into gaining access to this very hard-to-reach population. Because of the extensive time commitment, only two (English-speaking) respondents were recruited this way.

Recruitment for Spanish-language interviews was perhaps more difficult. Flyers similar to the English version were initially sent to as many community organizations as possible and additional efforts were made to visit substance abuse treatment centers or clinics in person. Neither strategy was successful. There was no response to the flyers and organizations were unwilling to assist. Recruitment efforts then shifted to visiting WIC offices, and posting flyers electronically on different Facebook groups, but difficulties remained.

There was a lack of response to flyers posted publicly and on Facebook for two important reasons, neither of which had anything to do with the subject matter of the study. Both concerns were directly expressed to the recruiter by many potential participants. First, coinciding with the timing of recruitment, Immigration and Customs Enforcement (ICE) agents were conducting raids on undocumented immigrants. This discouraged people (particularly those who were monolingual and undocumented) from responding to flyers, as they were

³ The earlier study can be found at <https://wwwn.cdc.gov/qbank/Reports.aspx#/Reports/1201>

seen as possible traps. Second, media reports were circulating a story of two local women who had used a Facebook group to find and lure a pregnant woman in order to abduct her baby.

Due to concerns such as these, it took extensive effort to gain the trust of potential participants by answering all their questions and building rapport. Once trust was established, respondents were asked to share the study information with any other mother they thought might be interested and would qualify. The majority of respondents were recruited with this chain referral strategy; however, many did not meet the original criteria of having used prescription pain relievers, non-prescription drugs, alcohol, and tobacco products after the birth of their baby. As a result, questions on substance use and treatment/counseling questions were not extensively tested in the Spanish-language interviews. Instead, other items, such as experiences with the healthcare system, infant development, and respondent childhood experiences were the focus of these interviews.

Table 1 summarizes demographic composition by language. Spanish-speaking respondents were slightly younger and had less education than the English-speaking respondents. Additionally, respondents in the Spanish interviews had younger children than in the English interviews. The oldest child in the sample was five years of age, but the majority fell within the originally-recruited age range of two to 18 months.

Table 1: Demographic Summary of Sample by Language and in Total

	English (n=18)	Spanish (n=16)	Total (n=34)	
	Number	Number	Number	Percent
Age of respondent				
Under 30	1	5	6	17.6%
30 – 34	6	7	13	38.2%
35 – 39	4	3	7	20.5%
40 – 44	4	1	5	14.7%
45 and over	3	0	3	8.8%
Education				
High school diploma or less	9	15	24	70.6%
2- or 4-year college degree	7	1	8	23.5%
Graduate degree	2	0	2	5.9%
Race/Ethnicity				
Non-Hispanic White	2	0	2	5.9%
Non-Hispanic Black	13	0	13	38.2%
Hispanic	1	16	17	50.0%
Asian	1	0	1	2.9%
American Indian/Alaska Native	1	0	1	2.9%
Age of child				
9 months or less	5	8	13	38.2%
10 – 18 months	5	6	11	32.4%
19 months and over	8	2	10	29.4%
Version tested				
Telephone	16	8	24	70.6%

Self-administered	2	8	10	29.4%
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Analysis of the interviews included a three-stage process similar to the constant comparative method first developed by Glaser and Strauss (1967)⁴ and adapted to cognitive interviews by Miller et al. (2014).⁵ Data analysis was conducted with the use of Q-Notes, a software application specifically designed for cognitive interview studies.

Every interview was first summarized into notes describing the ways in which respondents answered each question. These summaries include interpretations of key terms (such as prescription pain reliever and treatment or counseling), experiences considered by respondents when answering, and any response difficulties and errors they encountered, including whether the questions seemed inappropriately sensitive.

Next, comparisons were made across all interviews to identify interpretive patterns (including patterns of response errors) and to develop larger conceptual themes explaining the question-response process. Finally, a third level of analysis was conducted across subgroups of respondents to determine whether patterns tended to vary by group, for example by language. Quotes from individual interviews are presented as data to illustrate patterns and themes that have been developed with the constant comparative method.

An overview of key findings is described next, followed by a question-by-question analysis of all items tested.

Summary of Key Findings

Questions Related to Treatment and counseling

One of the aims of testing was to examine the performance of the questions related to substance use, and treatment and counseling related to those substances. However, because of the recruitment difficulties discussed earlier, all questions related to treatment and counseling were not thoroughly tested and those that were occurred only in English. The only exception was the first question in the series, question 8, ‘Since your baby was born, have you needed treatment or counseling for your use of [prescription pain relievers, drugs or medications other than prescription pain relievers, alcohol, cigarettes, drugs, or other tobacco production, any other substance]?’ All 34 respondents, even those who answered ‘no’ to all substances, were probed on their understanding of what the question was essentially asking. Interpretations were consistent, as most respondents thought the question was asking about needing help with addiction to those substances.

Only seven of the 34 respondents filtered into the follow-up treatment and counseling questions. All were English interviews. Four respondents answered for cigarettes alone, one for cigarettes and prescription pain relievers (hydrocodone), one for drugs other than prescription pain relievers (heroin), and one for drugs other than prescription pain relievers (heroin) and alcohol. Note that the last two respondents also used prescription opioids, but did not see themselves as needing or receiving treatment for their use because they took them as prescribed.

⁴ Glaser, B. and Strauss, A. (1967) *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Hawthorne, NY: Aldine de Gruyter.

⁵ Miller, K., Willson, S., Chepp, V., & Padilla, J.-L. (2014) *Cognitive Interviewing Methodology: A Sociological Approach for Survey Question Evaluation*. Hoboken, NJ: Wiley.

While the topic could not be fully studied from only seven interviews, a theoretically meaningful pattern of interpretation began to emerge in the data. Question 8 was understood as a question about addiction and this influenced the way respondents interpreted aspects of other questions. For example, the contextual effects of question 8 caused inconsistent interpretations about the list of substances in the treatment and counseling questions. Specifically, cigarettes and prescription pain relievers (opioids) did not function the same as the other substances.

First, smoking cessation efforts were not always understood as the type of ‘treatment and counseling’ aimed for in this question. For example, one respondent who discussed quitting with her doctor did not think that should be included in this question and answered that, no, she did not *receive* treatment or counseling for her use of cigarettes even though she reported *needing* treatment or counseling for help quitting cigarettes. Because she quit on her own, and not by any method prescribed by the doctor, she judged this as not receiving treatment or counseling. Smoking cessation was not understood as falling into the same category as treatment or counseling for non-prescription drugs and alcohol abuse.

Second, two respondents who were in treatment for heroin (and alcohol) did not include their use of opioids because they either took these prescriptions as directed or did not finish the prescription. This further suggests that substances are differentially associated with the concept of addiction and recovery and respondents may omit certain experiences as a result. Further study would be needed to saturate this category of interpretation.

Sensitive Questions

Another aim of testing was to explore the extent to which respondents provided socially desirable answers to questions that were deemed too sensitive to answer on a survey. Despite the topics covered in the questionnaire, respondents generally answered the questions and seemed to give genuine and thoughtful answers. However, three items did elicit answers and reactions that suggest the topic was too sensitive and contributed to a certain level of discomfort (or even indignation) among some respondents, making these questions more prone to response error and missing data. For two items, the issue was linked to the contextual effects of the substance use and treatment/counseling questions discussed above.

The first item that may prompt socially desirable (or missing) responses is question 17, item c. This question asks why a health provider suggested the respondent NOT breastfeed her baby. The reason for item c is ‘there was concern that drugs or medications you were using would pass to the baby through your milk’. This seemed like the best answer for two respondents who did not choose it because they believed it conveyed the idea that they were using illicit drugs when in fact they were on legitimate medication for preexisting conditions (high blood pressure and thyroid disease).

A second question that can be potentially off-putting to respondents (and thereby elicit response error or missing data) is question 24, ‘Were you and baby discharged from the hospital at the same time after birth?’ The question in-and-of itself is not offensive, but one respondent found it so in the context of this questionnaire. She specifically argued that the previous questions about “have you had any history with drug abuse” convinced her that the questionnaire overall was seeking to assess her fitness as a mother. She immediately interpreted the question as asking whether the baby was *permitted* to leave the hospital with her.

Finally, the last question (34) contains a list of 11 difficult experiences the respondent herself may have had while growing up. Most items were not perceived as inappropriately sensitive and respondents were willing

to answer them. However, item d, ‘Did you live with anyone who was a problem drinker or alcoholic’, stood out as an exception. Multiple respondents expressed discomfort describing their parent as “alcoholic”, even if they were willing to discuss the idea that their parent may have used alcohol more than was reasonable or healthy. Even those who answered ‘yes’ to the question still expressed discomfort or doubt about their answer.

Details of these findings are discussed next in the question-by-question analysis. The patterns that were discovered were consistent among respondents; in other words, there were no remarkable differences of interpretation by any demographic characteristic, including language. The few differences that were observed are noted by question.

Question-by-Question Analysis

The first questions are about you and your health.

1. I’m going to read a list of health conditions. For each one, please tell me if you *currently* have it. Do you have ___?

Condition	No (1)	Yes (2)	Refused (8)	Don’t know (9)
	a. Depression			
b. Anxiety				
c. Hepatitis B				
d. Hepatitis C				
e. Chronic Pain, which is pain lasting more than 12 weeks or 3 months				

Findings: This question did not pose significant difficulty for respondents; however, two problems were identified. First, the word ‘chronic’ in item e was not consistently understood by all respondents, and despite the definition that follows the term, some still answered incorrectly. For example, one respondent answered ‘yes’ to chronic pain although she was thinking about temporary pain which lasted no longer than a month after her C-section delivery. Another respondent also reported chronic pain but asked, “Can it be on and off? I have high blood pressure so when my pressure’s really high I get bad headaches.” She was not sure if ‘chronic’ had to be constant or if having periodic pain was also sufficient. Others associated chronic pain with intensity rather than duration. This resulted in response error. For example, one respondent answered ‘no’ to this question even though she had constant headaches. She answered ‘no’ because the pain was not intense. She explained, “I have a lot of headaches and sometimes it is very often.” When asked what she thought chronic meant she said, “Very strong. It [her headache] is not strong, but it is regular.”

Second, the items in this question rely on two different kinds of assessments. For example, Hepatitis B and C are essentially known only through formal diagnosis. Therefore, providing an answer is relatively straightforward – a respondent either has received this diagnosis or has not. Problems with reporting are associated largely with memory. For example, one respondent did report Hepatitis C but was not positive of the diagnosis. She said, “I think I have Hepatitis C, but I’m not sure. I do not remember which one I have. I do have one, but I don’t remember which one it is.”

The other items – depression, anxiety, and chronic pain – are more subjective states that respondents feel. This is further complicated by the fact that depression and anxiety may or may not have a diagnostic component. As a result, respondents must make a decision whether to include only diagnosed conditions or also feeling states. Some decided that only diagnosed conditions count. One respondent answered ‘no’ but during probing said that since the birth of her child (who was 22 months old) she had been depressed, which she described as feeling anxious, sad, hopeless, and guilty. When asked why she answered ‘no’ she said it was “not diagnosed”. However, others made the opposite judgment and included undiagnosed feelings. During probing one respondent said that even though she had not been diagnosed with anxiety she answered ‘yes’ because, “Sometimes I get desperate. I get nervous and I get very hungry.” Another also answered ‘yes’ to anxiety but added, “Yes. Not diagnosed, but yes. So I don’t know if that makes a difference.” She decided it should be included. Respondents who had received formal diagnoses had less difficulty because they did not have to make this judgment. One said, “Yes, I was diagnosed since I was 15 or 16 years old. I was going to therapy and everything was fine. But I stopped going...because of school I couldn’t go anymore.” Another also said, “A doctor...I am actually medicated to control depression.”

2. *Since your baby was born*, how many health care visits have you had with a doctor, nurse, or other health care worker, including a dental or mental health worker? Do not include any home visits you may have had by a doctor, nurse or other health care worker.

- 1 Number of Visits [_____]
- 2 Have not had any health care visits since baby was born

Findings: There were two difficulties with this question. First, it was unclear who was being referenced. Even though ‘you’ is underlined and in italics in order to guide the respondent to include only visits for herself, the clause ‘since your baby was born’ prompted some respondents to think that visits for the baby should be included. One respondent heard the question and said, “I have to think about that. Now are those visits for her [the baby] or for all of the above [conditions in question 1]?” The interviewer re-read the question, again emphasizing ‘you’. The respondent replied, “For me? Oh, for me? I’ve had two or three.” That interview was a telephone administration, but mode did not make a difference. Another respondent with the self-administered version made the same mistake. She included visits for her baby. During probing the interviewer pointed out the underlined ‘you’. The respondent explained how she assumed the question was about the baby based on past experience with other questionnaires. She said, “I had to fill out a questionnaire before [in other places] and they asked me how many doctor visits the baby had since he was born.” Another respondent also at first thought the question was about the baby. She asked, “This question is asking how many visits to the doctor I have had since my baby was born. Who? Me or the baby?” The interviewer asked for her opinion. “The baby, no?” The interviewer read the question again. “Oh, no. It’s asking about me.”

The second problem relates to recall difficulty for respondents with many medical visits. Some could not remember every visit and provided what they acknowledged were estimates. Their reactions indicate their difficulties:

It was a lot.

At least a dozen.

Hmm...a lot. I mean, I can't really count. I've had several postpartum visits and then my own health visits. You know, GYN and all that. So I don't know...I would say maybe eight. That would be a rough estimate.

For me...umm...four, I think...I don't know. I can't really remember. I also have other health things that don't really have anything to do with the baby, so...

3. What type of health care visit have you had since your baby was born?

Types of Visits	No	Yes	Refused	Don't know
	(1)	(2)	(8)	(9)
a. Postpartum checkup				
b. Visit for problems I was having related to the delivery of my baby				
c. Regular checkup at my family doctor's or OB/GYN's office				
d. Visit for an illness or chronic condition				
e. Visit for an injury				
f. Visit for family planning or birth control				
g. Visit for depression or anxiety				
h. Visit to have my teeth cleaned by a dentist or dental hygienist				
i. Prenatal care visit for a new pregnancy				
j. Have you had another type of health care visit?				
k. If YES, ask: What type of visit?				

Findings: The most problematic items in this series were a, c, and f. In the first item some respondents did not know what counted specifically as a postpartum visit or were unfamiliar with the word altogether. For example, one respondent said, "Postpartum? Is that when you deliver the baby before the due date? That's why I did not mark that option." Further discussion revealed she likely did have a postpartum visit but included it under item c (regular checkup). She said, "It was a check-up visit after I delivered the baby."

Other respondents defined postpartum not in terms of the purpose of the visit but in relation to the provider, usually gynecologists. One respondent asked, "Is that your gynecologist?" She decided it was and marked 'no' because she saw her family doctor after the birth of her baby. Another respondent had a similar pattern. She marked 'yes' to postpartum but then got confused when she heard c (regular checkup). She said, "Well, I would kind of think that that would be the postpartum, but I don't know. Because when you said postpartum, that is with the OB/GYN I would assume. But I don't know. I have a private doctor."

Other respondents defined postpartum as depression (confusing it with the term 'postpartum depression'). One respondent said, "Postpartum checkup?...it is when somebody has depression. Isn't it?" Another said, "I do not understand it [postpartum] very well. I don't know how to explain it...I only heard about postpartum depression. It is like when you deliver the baby and then you have the depression." Finally, one respondent answered 'no' to postpartum because she was not certain. She said, "That would be, for example, if I have postpartum depression...or is it after I have given birth?" When asked what she thought, she replied, "I understand, from what I have heard, it is for those women who suffer from depression after giving birth, that they do not love their baby – they reject him or her."

Items a, c, and f were also confusing because the activities for each could be accomplished in one visit with a single provider or at different visits with multiple providers. Some respondents indicated this experience as a single visit. For example, one respondent marked ‘yes’ to postpartum but ‘no’ to birth control. About her postpartum visit she said, “In that checkup we talked about how to prevent more pregnancies and we decided to insert the...I forgot the name. It’s like a [IUD].” Another respondent who marked ‘no’ to birth control also said, “Family planning and birth control I took care of during my postpartum visit.” If the intent is to capture the purpose of the visit – reasons why respondents visited doctors – and they mark only one category, it may mistakenly appear as though they did not receive certain types of care, such as birth control.

Other respondents did the opposite and answered multiple categories even when the activities occurred in a single visit with one provider. For example, one respondent marked ‘yes’ to a, b, c, and f; however, all took place during the same visit with her family doctor. Another respondent marked ‘yes’ to a, b, and c for the same reason. She said, “Some of it [reasons for the visit] was for complications I was having [yeast infections, pelvic pain, blood pressure, blood sugar]. Most of it was for the OBGYN [reasons].” Another respondent also counted these as separate categories and marked ‘yes’ to a and f even though she saw one doctor “on the same day”. The intent of the question is unclear. If the intent is to capture number of doctor visits – irrespective of the purpose for the visit – and respondents mark ‘yes’ to multiple categories that occurred on the same visit, it may appear as though they visited doctors more often than they did.

4. During any of your health care visits *since your baby was born*, did a doctor, nurse, or other health care worker do any of the following things?

	No (1)	Yes (2)	Refused (8)	Don’t know (9)
a. Talked to you about managing pain after the birth of your baby				
b. Asked you, in person or on a form, if you drank alcoholic beverages				
c. Asked you, in person or on a form, if you smoked cigarettes or used other tobacco products				
d. Asked me if I was feeling down or depressed				

Findings: This question was straightforward for most respondents to answer, as they had specific memories of conversations or materials given to them. When probed on their experiences, respondents gave similar explanations:

Every time I had an appointment and even the day of delivery, which was really fast, they asked me general things. During every visit they would ask me these things.

When I went to see the doctor in April these are questions that we are always asked. In case they [the doctors] prescribe us some medication, they have to know if we drink alcohol, smoke, or use street drugs so [we] don’t have a bad reaction.

They give you a questionnaire where you have to answer how many days a week you feel sad...and also questions related to alcohol and tobacco. You give the questionnaire back to the nurse and then you discuss it with your doctor.

They gave me some forms to fill out and they also talked to me once or twice. But mostly using the forms.

Yes, they always gave me the questionnaire.

When I went to my appointment after the C-section I filled out a questionnaire and I had to answer these questions. I have to fill out a questionnaire every visit that I have.

When you come in they give you a list. Asking about do I smoke, any problems I have. Anything I check off, a counselor or therapist comes and talks to you about the issues that were checked. And she just talked to me about stop the smoking. Which I did before I had the baby.

Some respondents included even brief conversations. For example, one respondent said, “They just asked me have I smoked cigarettes, have I drank alcohol? Which is not healthy for the baby.” Another said, “It wasn’t much of a conversation, it was more of a packet. It was more of review this packet and if you have any questions about anything in particular [then ask].” One respondent explained the rationale for only a brief conversation. “I’m not a heavy drinker. They kind of know my history so they didn’t go in depth. They just kind of touched the surface on that.”

Although most respondents answered the question without difficulty, some were unclear about the timeframe, ‘since your baby was born’. The confusion was over whether to include conversations that took place in the hospital or only those that occurred after the respondent and baby were discharged. Some were thinking specifically and only of hospital encounters, especially in relation to the first item, pain management. One respondent said, “Umm...well I guess that was done at the hospital. Because you go back to a gynecologist weeks later [when the pain would be gone].” The following are examples of others who also answered ‘yes’ when thinking of discussions in the hospital:

They talk to you even before you leave the hospital.

It was in the hospital, the nurses asked me all those questions.

Yes, the nurse asked me these questions. She also gave me a questionnaire to fill out...this was still at the hospital, right before dismissal.

5. I’m going to read a list of *prescription* pain relievers. For each one, please tell me if you used it *since your baby was born*. Please include any medications that you may have taken to relieve pain associated with your baby’s birth. Did you use _____ since your baby was born?

Prescription pain reliever				
	No (1)	Yes (2)	Refused (8)	Don’t know (9)
a. Hydrocodone like Vicodin®, Norco®, or Lortab®				

b. Codeine like Tylenol® 3 or 4, these are <u>not</u> regular Tylenol®				
c. Oxycodone like Percocet®, Percodan®, OxyContin®, or Roxicodone®				
d. Tramadol like Ultram® or Ultracet®				
e. Hydromorphone or meperidine like Demerol®, Exalgo®, or Dilaudid®				
f. Oxymorphone like Opana®				
g. Morphine like MS Contin®, Avinza®, or Kadian®				
h. Fentanyl like Duragesic®, Fentora®, or Actiq®				

Findings: Most respondents could answer this question because they knew the name of the opioid they took. Some respondents had been taking opioids prior to and after delivery. For example, one respondent easily chose Tramadol because she had been taking it for six or seven years for headaches. She said, “It’s my ‘mom medicine’. I’ve been taking it so long.” Another long-term user said, “Yes, hydrocodone, yes.” She had chronic pain due to sciatica. “I said I wanted to come off the Hydrocodone and they gave me the Tylenol 3’s. The Hydrocodone, sometimes I felt like I was just too drugged-up to be home with the baby by myself. But the Tylenol 3s will allow me to function.” Other respondents used opioids both with and without a prescription. One respondent said, “The Oxy[codone] was prescribed to me but the Fentanyl wasn’t.” The interviewer asked if she bought it on the street. “Yeah, because a lot of heroin is cut with Fentanyl.”

Many other respondents thought of the opioids they were administered while in the hospital after delivery. For example, one respondent said, “The only medication that was prescribed with my son and my girl was the hydrocodone to relieve the pain after the C-section. But that’s it.” Another chose morphine and explained, “After my baby was born they gave me morphine because I had a procedure done. I had a hemorrhage and to stop it they gave me morphine three times. It was very painful.” One respondent could not remember if the Tylenol she was given in the hospital was Tylenol 3 or 4, but knew it was not over-the-counter. She said, “They gave it to me because I had surgery to prevent having more babies...That same day [as delivery]. They didn’t give me the medicine because I had given birth, but to help with the pain from the surgery.”

Because administration of the opioid occurred in the hospital, some respondents were not sure of the name of the drug, but were able to identify it on the list. One respondent chose hydrocodone and said, “I can’t remember the names, but when you mentioned it, it sounds really familiar.” Another respondent was less certain because it was given only in the hospital and was not something she took home. “Yes, that was a very strong medication, so the nurse told me not to take them very often because you can become addicted...I think it was this [points to item a], Hydro...”. Another respondent also had a difficult time because the opioid was administered only in the hospital. She chose morphine but was not certain. “Does Ibuprofen have the first one you mentioned [morphine]? Because I’ve heard that before but I’m not sure if it’s the ingredient in Ibuprofen.” The inability to identify the opioid name was more likely to happen when it was administered only in the hospital.

The above respondents were thinking exclusively of their delivery experiences in the hospital. Other respondents included opioids administered in the hospital *and* prescriptions they took at home, but all were still in relation to childbirth. For example, one respondent answered Tylenol 3 and Percocet. “I was given Percocet for pain related to the C-section. I was really in a lot of pain. In the hospital I was more open to taking it because I didn’t have to chase my two-year-old. I was able to take it as prescribed.” But that changed once she got home. She could not function on Percocet so they gave her Tylenol 3. Even then she

could not take it as prescribed. “I took it when I really just could not bear the pain. Maybe at nighttime when they [her children] were asleep.”

Other respondents included opioid use associated with experiences aside from their most recent delivery. One respondent said, “The Percocet they gave me because I had a C-section. The Tramadol has been since I’ve had the baby because I have knee problems. And the Tylenol [3] was when I got my teeth pulled. That was all since I’ve had [the baby].” Another respondent also discussed different experiences related to the need for prescription pain relief that ultimately led her to a treatment program. She said, “This was after I had my daughter. My body started to shift and go through some changes. My head was hurting all the time. My knees started hurting. It was like different reasons. I’m only 37! But I really started doing a lot of stuff like...so it was Percocet, it was oxycodone, it was Tramadol. Stuff like that.”

Finally, only one response error was identified. It occurred in the Tylenol 3 category. One respondent chose this answer when the prescription pain reliever she took was high-dose Ibuprofen prescribed by the doctor after her C-section. She included it because it was, as item b reads, ‘like Tylenol 3 or 4’. In other words, it was a prescription-strength version of an over-the-counter pain reliever.

6. *Since your baby was born, for how many week or months have you used prescription pain relievers? Please tell me the total number of weeks or months you have used prescription pain relievers since your baby was born.*

1 Number of weeks _____

OR

2 Number of months _____

3 Less than a week

Findings: One difficulty that emerged for this question was among those respondents who took more than one type of opioid or multiple medicines at once. Some respondents, thinking the question was asking primarily about pain relief, included all medicines, not just the opioids referenced in the previous question. For example, one respondent was taking Tylenol 3 and prescription-strength Ibuprofen for different reasons after her delivery. She took them for different lengths of time and had to calculate the duration of use for each. She said, “I, of course, had the pain relievers for almost three weeks after she was born. I also had some tooth issues, so I used pain relievers for another two, three months. I also used them for another two months because I have really bad cramps. I’ll just take the medication I was given for those.” Another respondent also thought of both prescription-strength Ibuprofen and the opioids she was given. She answered “Less than a week...Because after giving birth I had a headache and was prescribed Tylenol 3 and Ibuprofen. And they also gave me morphine that day [of delivery].” Another included Norco and her migraine medicine, Sumatriptan. She answered “eight weeks” but had a difficult time disentangling how long she took each one.

The clause ‘since your baby was born’ functions not only as a timeframe but can also tilt the intent of the question towards those pain relievers that were taken specifically in relation to the birth. This caused difficulty when pain relievers were taken for different reasons. For example, one respondent was taking Tramadol up to and including the time of the interview, which was four months. However, she (under)reported only six weeks because she was including its use specifically and only for delivery-related pain.

Additionally, the phrase ‘prescription pain relievers’ may cause some to exclude opioid use without a prescription. For example, one respondent answered two weeks, thinking of the Percocet prescription she was sent home with from the hospital. However, she did not include the Fentanyl she bought on the street. For Fentanyl she explained, “I had been using it before and while I was pregnant...I just got back into it [after delivery].” When asked why she answered only two weeks she said, “Two weeks because that was the length of the prescription.”

The concept of ‘prescription’ was cause for other confusion as well. Some thought of the length of time as directed by the prescription, others thought of the length of time actually taken. For example, one respondent took Percocet after her C-section for about a month, sometimes less often than prescribed. However, she answered for the length of the prescription *if taken as directed*. When asked about her answer of two to three weeks she said, “I think they give three-week’s worth or two-week’s worth.” Conversely, another respondent answered not for the length of the prescription as written, but for the length of time she *actually* took Tylenol 3. She said, “After that [the initial pain after delivery] it was like if I had some really bad pain. It could have been a headache and I still had one of those Tylenol 3. I would just take one of them. But this wasn’t pregnancy related. This was just leftover Tylenol [3] that I had.”

7. *Since your baby was born*, how often have you used the following tobacco products? I’m going to read a list of options. For each one, please tell me **Every day** if you have used that tobacco product *since your baby was born*, **Some Days** if you have used it occasionally *since your baby was born*, or **Never** if you have not used it. Did you take or use _____?

Tobacco Products	Every day (1)	Some Days (2)	Never (3)	Refused (8)	Don’t know (9)
	a. E-cigarettes or other electronic vaping products with nicotine				
b. Hookah					
c. Chewing tobacco, snuff, snus, or dip					
d. Cigars, cigarillos, or little filtered cigars					

Findings: Most respondents had no trouble understanding these products even though most reported never using them. However, the term ‘tobacco products’ in the initial question cued some respondents to think of regular cigarettes and were not sure where to report them on this list of items. One respondent mistakenly answered ‘some days’ to d (cigars, cigarillos, or little filtered cigars) because she thought it said cigarettes. When asked about cigars during probing she said, “No. Cigarettes. I didn’t see that [cigars, etc].” This mistake occurred in Spanish as well, but may have been due more to a translation issue, as the word ‘cigarillors’ was translated into the word ‘cigarette’.

8. *Since your baby was born*, have you needed treatment or counseling for your use of...

Substances	No (1)	Yes (2)	Refused (8)	Don’t know

				(9)
a. Prescription pain relievers				
b. Drugs or medications other than pain relievers				
c. Alcohol				
d. Cigarettes or other tobacco products				
e. Did you need treatment or counseling for your use of any other substance?				
f. If YES, ask: For what?				

Findings: Only seven respondents answered yes to any of the substances, but all respondents were probed on their understandings of treatment and counseling in the context of this question. Sometimes these terms were understood differently. For example, in some cases ‘counseling’ was understood as the directions for use and explanations of side effects associated with prescription pain relievers. In contrast, the word ‘treatment’ (especially in the case of prescription pain relievers) was understood as the medication itself to manage pain.

Even though counseling and treatment could be understood as different activities, most respondents understood the question as asking about needing help for addiction to these substances. Explanations were fairly consistent and included:

When you need help because you are drinking, smoking, or using drugs too much and you cannot control yourself. You cannot live with them. That is when you need to ask for help.

That if you have an addiction problem and need help to stop using, then you need to go to counseling.

If I had trouble with alcohol, go to see a specialist because I am abusing alcohol.

I’m thinking of people who go into rehab.

Like treatment you receive so you don’t drink anymore or stop using drugs.

Did I have a problem with any of it – did I have an addiction problem.

Sometimes you receive treatment, they help you get rid of your vice with drugs, cigarettes...If you have that problem, they help you get rid of it. Since I didn’t have that problem, I didn’t need anything.

Did you have to go to a treatment program for your drug addiction or alcohol addiction or type of addiction. Or did you need counseling. Did you need to talk to somebody about that.

Of the seven respondents who answered ‘yes’ to one of the substances, all were in the English-speaking interviews and four of the seven were for cigarette cessation. Those who answered for cigarettes were thinking of a variety of strategies such as discussions with their doctors (“Well, I talked to my doctor about stopping smoking and eventually I lost a taste for it.”), the use of products such as nicotine patches (“Yeah, the doctor told me about that. And they gave me the patch and then they gave me some kind of gum.”), and social media support groups (“There’s a group of moms that I belong to. We’re like a support group and some of those people kind of encourage me to stop smoking”).

One respondent reported ‘yes’ for prescription pain relievers. “Have I needed treatment or counseling? Yes, I have. For the Hydrocodone.” When asked what that involved she said, “My doctor had a pain management doctor come in and speak with me about weaning me off of that and try not to take it as often. Told me about serious side effects of it.”

Two respondents answered ‘yes’ to ‘treatment or counseling for your use of any other substance’. Both were in a six-month treatment program for new mothers. Both used prescription opioids along with heroin but did not mark ‘yes’ to ‘prescription pain relievers’ because they did not misuse opioids obtained through prescription – they either took the prescription as directed or took less than directed because they traded the rest for heroin. As one respondent explained, the help she thought she needed was for heroin, not prescription opioids: “Even though I wasn’t mismanaging my medication [Percocet by prescription], I was still using other things [Heroin with Fentanyl] while I was taking medication.” Both were thinking about their misuse of heroin that led to the need for treatment.

9. Since your baby was born, have you received treatment or counseling for your use of...

Substances				
	No (1)	Yes (2)	Refused (8)	Don’t know (9)
a. Prescription pain relievers				
b. Drugs or medications other than pain relievers				
c. Alcohol				
d. Cigarettes or other tobacco products				
e. Drugs				
f. Did you receive treatment or counseling for your use of any other substance?				
g. If YES, ask: For what?				

Findings: All but seven respondents were instructed to skip past this question, so it was not well tested. Those who smoked had different reactions to this question. Two were in support groups for smoking cessation. However, they each had a different interpretation on whether that counted as receiving treatment. One did count it and answered ‘yes’; the other did not and answered ‘no’. One respondent answered ‘no’ because she ultimately cut back on her own. Even though she did discuss the problem with her doctor, she did not include that as treatment or counseling in this question. The other answered ‘yes’ because she was using the nicotine patch provided by her doctor.

Two respondents who were in the six-month treatment program answered ‘yes’ (to f). As one respondent explained, “I’m receiving treatment now due to the relapse [two months ago]...After eight years [clean]. Look, before the eight years I used for 14 years.” The other respondent said, “Before I came here I was going to the doctor for Suboxone.” When asked why she ended that she said, “It seems like you’re replacing one drug to another.”

One respondent answered ‘yes’ to ‘prescription pain relievers’ because she was seeing a pain management doctor to try to eliminate the need for opioids.

10. I'm going to read a list of reasons why some people may not get the treatment or counseling they need for their use of any medications, drugs, alcohol or tobacco products. For each one, please tell me if it was a reason for you. Was it because _____?

Reasons				
	No (1)	Yes (2)	Refused (8)	Don't know (9)
a. You could not get an appointment or were put on a waiting list				
b. You was able to cut down or stop using without help				
c. You didn't think I needed help				
d. You didn't have enough money or insurance to pay for services				
e. You didn't know where to go for help				
f. You didn't have transportation				
g. You didn't want people to think you had a problem				
h. Your partner did not want me to get help				
i. You were afraid to lose custody of your baby or children				
j. You had too many other things going on				
k. Was there another reason?				
l. If YES, ask: What was it?				

Findings: This item was not well tested because, per the skip instructions, most respondents skipped out. Because only four respondents were administered the question, firm conclusions cannot be drawn. However, this question has the potential to cause difficulty because it asks respondents why they did not engage in a particular behavior. One respondent illustrates the difficulty. She chose options c, g, and j. But when asked to explain the reason in her own words, none of these options capture the essence of her rationale. She said, "I don't believe in counseling...I just know a lot of counselors, they sit there and teach you all these methods and they themselves don't follow. So it's a hypocrite." Questions that ask respondents why they did NOT do something often elicit answers that are not reliable.

11. *Since your baby was born*, which of the following types of treatment or counseling have you received? I'm going to read a list of types of treatment of counseling. For each one, please tell me if you received it. Was it _____?

Types of Treatment or Counseling				
	No (1)	Yes (2)	Refused (8)	Don't know (9)
a. Individual counseling with a behavioral health professional				
b. Group counseling with a behavioral health professional				
c. Counseling with a clergy member or other religious or community counselor				
d. Self-help or recovery group meetings (such as Alcoholics Anonymous, Self-Management and Recovery Training (SMART), Moderation Management (MM))				

e. Medication-assisted treatment (MAT) using medicines such as methadone, buprenorphine, Suboxone®, Subutex® or naltrexone (Vivitrol®).				
f. Tobacco cessation counseling or treatment				
g. Did you receive another type of treatment or counseling?				
h. If YES, ask: What did you receive?				

Findings: This question was not well tested because it applied to only four respondents. Others were instructed to skip. However, several points of confusion did arise, suggesting the need for further evaluation. For example, one smoker marked ‘yes’ for individual counseling (a). She was thinking of the psychiatrist she saw specifically for Post Traumatic Stress Disorder (PTSD). She included it because sometimes the subject of smoking comes up. “That’s when I’m just talking to my therapist about myself...about cigarettes, about mental health.” It’s unclear whether this should be included as treatment for smoking because the point of treatment was to address her PTSD. She also marked ‘yes’ to group counseling for smoking cessation that she attends once a week. “We sit in the group and talk about what we’re going through. We reach out to each other if we need to talk to somebody. It’s a stress reliever.”

Another respondent marked ‘no’ for individual counseling even though in her six-month treatment program she routinely speaks with a psychologist. When asked why she excluded that she said, “So I’m with a mental health doctor, but not for behavior. See, I do mental health. I do therapy sessions, not *behavioral*.” She also answered ‘no’ for group counseling, even though the program includes daily group sessions. When asked why she excluded those sessions she said, “Because they are just a group session...you still learn stuff...it’s a group setting because we have to do everything in a group...like we eat as a group. But it’s not *counseling*. We’re not counseled.” These responses suggest that some of these items have varied interpretations that may fall outside the intended scope of the question.

12. *Since your baby was born*, where have you received treatment for your use of any medications, drugs, or alcohol, not counting cigarettes? I’m going to read a list of places. For each one, please tell me if you received treatment there. Was it in _____?

Places				
	No (1)	Yes (2)	Refused (8)	Don’t know (9)
a. Self-help group meetings				
b. A private doctor’s office				
c. An emergency room				
d. A hospital as an inpatient where I stayed at night				
e. A treatment facility as an outpatient where I did <u>not</u> stay at night				
f. A residential treatment facility where I stayed at night				
g. A prison or jail				
h. Did you receive treatment somewhere else?				
i. If YES, ask: Where?				

Findings: This question was not adequately tested because most respondents were instructed to skip past it. However, there are indications that some of the categories may not be well understood by respondents. For example, one respondent had difficulty with the term ‘self-help group meetings’ in terms of what to include. She answered ‘yes’ but was not sure. She said, “Yes. Guess you could say that’s what it is.” When asked about the source of her confusion she explained, “The self-help group is the girl in the [apartment] complex. She formed a group for mothers, elderly mothers. I would go to them every now and again.” In other words, it was unclear whether a group should be included if it was organized by a layperson.

Two respondents were undergoing treatment at a residential treatment facility where they were staying for six months – the duration of the program. Yet neither marked ‘yes’ for option f. Both marked h (somewhere else) and wrote in the name of the treatment program. For reasons unobtained during the interview, neither understood that their experience related to option f (a residential treatment facility where I stayed at night).

13. What was the outcome of the treatment or counseling you last received? Would you say that _____?

1	You are still in treatment	
2	You completed treatment, or	
3	You did not finish treatment	

Findings: This question was not well tested because only three respondents answered. Two answered ‘still in treatment’ and were, indeed, interviewed at the treatment facility. The third respondent chose option 2 (completed treatment). Although she was trying to discontinue both smoking and Hydrocodone, she answered only for smoking and said, “I would say I completed it. I’m no longer smoking. Yeah.” However, she was still seeing a pain management doctor for Hydrocodone. This question may be problematic for respondents who receive treatment for different substances from different places.

14. What were the reasons that you did not finish treatment or counseling? I’m going to read a list of reasons. For each one, please tell me if it was a reason for you. Was it because _____?

Reasons				
	No (1)	Yes (2)	Refused (8)	Don’t know (9)
a. You had a problem with the program				
b. You could not afford to continue treatment				
c. Your family needed you				
d. You began using medications, drugs, or alcohol again				
e. Was there another reason?				
If YES, ask: What was it?				

Findings: This question was not tested. All respondents were instructed to skip to the next question.

The next questions are about your experiences when *your baby was born*.

15. After your baby was born, did anyone suggest that you *not* breastfeed your new baby?

- (Don't Read) 1 No
2 Yes

Findings: Respondents were able to answer this question and remembered discussions they had that usually took place in the hospital. Most discussions involved exhortations to breastfeed. During probing respondents were asked what they remembered about the conversations. The following are examples of how they replied:

It was a big thing. It was a big deal to feed your baby breastmilk. They are big breastfeeding advocates.

When you're in the hospital, the nurses are kind of forcing you to breastfeed. But that was normal to me.

They said breastfeeding would be better. It's more natural. They suggested I do, but I didn't.

It was very much encouraged at the hospital. She was in the NICU for a couple of days so I had to go down there and breastfeed her.

Yes, they told me it was good for her to grow healthy. That it would help her grow during the first days.

No, but the doctor actually told me about the benefits of breastfeeding.

Eight respondents answered 'yes' to this question. There were a variety of reasons they were told not to breastfeed, including use of drugs or medications (including opioids and cigarettes), medical conditions (thyroid disorder and HIV), and difficulties with the breastfeeding process itself (such as lack of milk production or difficulties latching). No response error or difficulties were observed.

16. Who suggested that you *not* breastfeed your baby? I'm going to read a list of people. For each one, please tell me if they suggested you do *not* breastfeed your baby. Was it _____?

Items				
	No (1)	Yes (2)	Refused (8)	Don't know (9)
a. Your baby's doctor, nurse, or other health care worker				
b. Your doctor, nurse, or other health care worker				
c. Your husband or partner				
d. Your mother, father, or in-laws				
e. Other family member or relative				
f. Your friends				
g. Did someone else suggest you do not breastfeed your baby?				
h. IF YES, ask: Who?				

Findings: A total of only eight respondents were filtered into this question, so it was not well tested. The only difficulty was that the first two categories overlapped for one respondent. In other words, the baby's doctor

and the respondent's doctor was the same person. The respondent counted this doctor twice by marking 'yes' for both a and b. She said, "It's the same person to me because the same doctor that assisted me was the same doctor that delivered my baby."

17. Why did a doctor, nurse, or other health care worker suggest that you not breastfeed your baby? I'm going to read a list of reasons. For each one, please tell me if it was one a reasons for them. Was it because _____?

Reasons	No (1)	Yes (2)	Refused (8)	Don't know (9)
	a. You had a medical condition that made breastfeeding a problem for you			
b. You had a medical condition that made breastfeeding unsafe for your baby				
c. There was concern that drugs or medications you were using would pass to the baby through your milk				
d. Your baby had a medical condition and breastfeeding was not recommended				
e. Was there another reason?				
f. If YES, ask: What was the reason?				

Findings: This question was not well tested, as most respondents were instructed to skip. However, it may be difficult for some to choose among categories that might elicit socially desirable answers. For example, one respondent had a difficult time choosing between a and c. When she heard a she said, "I guess I could go there." But then she heard c and said, "I think that's the best one." When asked to explain her confusion she said:

So the medical condition is associated with the medication they had me on while I was there [in the hospital]. So I don't know if that's two separate things. So I had preeclampsia and was on blood pressure medication and magnesium and they didn't...they were also afraid that the blood pressure medicine would also slow down her [heart rate] so they wanted me to wait a few days. But I don't want to say 'yes' to that question [c] because it makes it sound like I was on some other drugs that I shouldn't have been on that might have hurt the baby. It was just the medication they prescribed to me the two weeks I was in the hospital before she came.

Another respondent also failed to choose c because even though she was taking medication for a thyroid condition that they did not deem safe for the baby, she did not read the question that way. When asked why she answered 'no' she said, "No because I was not taking drugs, I was taking medication."

The next questions are about your baby's health when he or she was a newborn.

18. After your baby was born, did a doctor, nurse, or other healthcare worker tell you that your baby had drug withdrawal sometimes known as neonatal abstinence syndrome or neonatal opioid withdrawal syndrome?

- 1 No
- 2 Yes

Finding: This question was not tested well because most respondents answered ‘no.’ However, most understood the nature of the question. The following are examples of what respondents thought the question was asking:

It’s when the mother is using drugs and the baby depends on them as well. And when the baby is born his body needs it, asks for the drug.

I have heard in the news or TV series that when some women use a lot of drugs or alcohol during their pregnancy, the baby gets used to the drug or alcohol. And when they are born, that is what they want...drugs or alcohol just like an alcoholic.

I guess when you do drugs and pass them on to your baby. So they are born used to the medication or whatever they are given during pregnancy. They need it and get really sick if you don’t give it to them.

That I used drugs during my pregnancy and that my baby has it in her system. That’s what I understand.

Only one respondent answered ‘yes’ and while the doctors did not use the terms in this question, she understood the meaning. She said, “They didn’t say ‘withdrawal’. They said that he had drugs in his system and he was going to end up staying in the NICU for a while so they could ween him off the stuff and make him comfortable.”

19. Did your baby receive any of the following types of special care or treatment to help him or her with drug withdrawal symptoms? I’m going to read a list of special care or treatments. For each item, please tell me if your baby receive it. Did your baby receive _____?

Reasons	No	Yes	Refused	Don’t know
	(1)	(2)	(8)	(9)
a. Medications such as morphine, methadone, or buprenorphine				
b. Fluids through an IV				
c. Skin-to-skin care or Kangaroo Care				
d. Sleeping in quiet, dimly lit room				
e. High calorie formula				
f. Breastfeeding or pumped breast milk				
g. Donor breast milk				
h. Did your baby receive other treatment?				
i. If YES, ask: What did your baby receive?				

Findings: This was not well tested, as all but one respondent were instructed to skip out. The one respondent who did answer was able to say ‘yes’ to a, b, and c. She knew that they gave the baby morphine, “And they had to ween him off that. It took forever.” She also knew that the baby had IV fluids but did not know

everything he was given intravenously. “They always had lines going through his belly button the whole time.” When asked what fluids she said, “I don’t really know. They didn’t explain a lot about that.”

20. I’m going to read a list of things that the doctors, nurses, or health care workers might do after your baby was born. For each one, please tell me if they did it after your baby was born, or not.

	No (1)	Yes (2)	Refused (8)	Don't know (9)
a. Talk to me about why my baby had drug withdrawal				
b. Talk to me about treatment for babies with drug withdrawal				
c. Talk to me about how long my baby’s withdrawal signs may last				
d. Talk to me about the things my baby could experience				
e. Talk to me about my baby’s behavior				
f. Talk to me about when my baby would be able to go home				
g. Ask me about medications I was taking or took during pregnancy				
h. Suggest I receive counseling or treatment for my use of medications, drugs or alcohol				
i. Suggest I receive services for my baby such as early intervention or home visiting programs				
j. Did a blood test or scoring test to evaluate my baby for neonatal abstinence syndrome				

Findings: This was not well tested because most respondents were instructed to skip it. Only one respondent filtered into the question. She answered ‘yes’ to all but two items and had no difficulty recalling these conversations. The respondent was currently in a treatment facility.

21. After your baby was born, how would you describe where he or she stayed most of the time during your time in the hospital? Did he or she stay _____ ?

- 1 In the hospital room with you, sometimes known as “rooming-in”
- 2 In the regular newborn nursery
- 3 In a specialized nursery for babies that need extra care such as a Special Care Nursery (SCN) or Neonatal Intensive Care Unit (NICU)
- 4 Baby was not born in a hospital

Findings: This question was easy to answer for those with straightforward, uncomplicated experiences. Most chose the first category. As one respondent said, “He was with me the whole three days that I was there. He was by my side the whole time.” Others understood that even if the baby was not in the room 100% of the time, the question was asking about most of the time. One respondent said, “Well, he had some tests like blood tests and stuff like that. But he was with me most of the time.” Another gave a similar response, “They

brought him to me and he slept with me. They would take him sometimes to get his tests done, but most of the time he was with me.”

Other respondents chose the third category because their baby had health problems. For example, one respondent said, “My baby was a preemie, so my baby was in the NICU.” Another chose the second option and said, “She’d stay in there [with the respondent], but after a while they come get the baby. After a certain amount of hours they would come get the baby. They don’t let the baby stay with you like half the night to let you figure out and get used to the baby.”

However, other respondents with more complicated experiences were inclined to provide two answers. For example, one respondent first said, “Kind of split between rooming in and the nursery.” When prompted for a single answer she chose 2 (nursery). In explaining the nature of her confusion, she said, “They would bring her by and I would feed her and family would see her. And I wanted her to go back to the nursery because otherwise people would never leave. So she would be up there for a few hours and they would take her back down to the nursery.” Another respondent also provided two answers. She said, “She stayed in the room mostly and then, like, they would take her to the nursery for a couple hours so I could sleep. So I don’t know if that’s both. But she was mostly in my room.” One respondent first chose the third category and said, “Well, he was in NICU because his sugar was kind of – I can’t remember if it was high or low. Because I had diabetes when he came out. But he was just in there overnight because his sugar came back to normal. After that, he came back in the room with me.” After thinking about it, she changed her answer to 1. Respondents were usually able to choose a single category, but it took prompting by the interviewer for them to do so. This would be problematic for the self-administered version.

22. Before you were discharged from the hospital after your baby was born, was a doctor, nurse or other health care worker able to answer any questions you had about your baby’s health?

- 1 No
- 2 Yes
- 3 You didn’t have any questions about your baby’s health

Findings: Almost all respondents answer ‘yes’ to this question. Some remembered details about specific conversations:

I always ask about any kind of shots or any time they came in the room and they wanted to do anything with the baby I am like questioning what’s going on. Why do they need that shot? Or if they want to take him and do the circumcision. I asked a lot of questions about the circumcision. I did ask about formula because I was thinking about doing both with him. What formulas are the closest to breastmilk?

With me being elderly and with complications, they gave me sites to go on. They gave me books to read, they gave me pamphlets. The nurses were good. They found another patient that was a year older than me and they asked if it was okay to share my phone number with her.

The issue with the baby’s tongue-tie. He also had trouble with his heart beat during labor. We asked all those questions because the baby had many tests to make sure everything was fine with him. I had an infection so we had to make sure the baby was healthy and fever-free.

Others did not remember specific conversations but assumed those types of discussions took place as needed. One respondent said, “Honestly, it’s like a casual conversation between my doctor and I. And he told me typical baby, healthy baby. So it’s not like we had anything else to discuss. And we didn’t have any family history of disease.” Another said “Yeah, I didn’t really need much. Mostly what I was asking was when he would be able to come home.”

Others answered ‘yes’ even when they did not remember having specific questions or extensive conversations. One respondent said, “More than me asking questions, the doctor told me that the baby was healthy, that there was nothing wrong with him.” When asked what questions she had, another respondent replied, “Just if everything was okay with him; if he had any problems. Just like that.” In general respondents were not inclined to choose the third category. For example, one respondent answered ‘yes’ but during probing said, “Everything was fine with me and with the baby...I had no questions regarding my baby’s health because he was healthy.”

Only two respondents chose the third category (no questions). One respondent explained that this was because she had multiple children and therefore had no questions. The second respondent said, “At the hospital I did not have much to ask, and at that moment I did not have questions.” One respondent initially chose ‘no’ but changed it to category 3 during probing. She said, “Oh, I made a mistake there, I should have answered ‘I did not have questions regarding my baby’s health’.”

23. I’m going to read a list of things that the doctors, nurses, or health care workers might talk to you about. For each one, please tell me if they did it before you were discharged from the hospital.

	No (1)	Yes (2)	Refused (8)	Don’t know (9)
a. How to soothe your baby				
b. How to respond to your baby’s needs				
c. Feeling a bond with your baby				
d. Feeding your baby at home				
e. Having a safe place for your baby to sleep				
f. Having someone that can help you take care of your baby				
g. Taking your baby to doctors’ visits				
h. Keeping your baby safe in your home				
i. Recognizing signs or symptoms in my baby that require medical attention				

Findings: Some respondents who answered ‘yes’ had clear memories of conversations regarding these topics. For example, one respondent said, “Honestly, it was a whole conversation. I didn’t even ask for it. The nurse just came in and gave me the whole spiel about all this stuff.” Several other respondents also remembered specific conversations:

Well they have a nurse that comes in and explains things about how to bond with your baby. You know, when you take your baby home. How to set up your home to make sure your house is ready for

the baby to come in. Sanitize things, making sure if you have people around how they're supposed to sanitize...Basically that was while I was in the hospital.

She [the nurse] just came in the room and did the test since she's a preemie – if she's tall enough to sit in her car seat. And making sure she cannot sleep in the same bed with me. I should make sure she is always in her crib with no extra bedding, no pillows. And not to dress her too warm and not to dress her too cold. And they gave me a list of clothing to wear at certain temperatures.

Like the respondent in the last example, those who had complications with the delivery or the baby's health tended to remember specific conversations because these items were especially salient to their experience. One respondent whose baby had initial health problems answered 'yes' to many items and said, "Yeah. Because she was in the NICU when I left and she was still in the hospital." Another respondent also answered 'yes' to all items because her baby also needed special care due to an early delivery. When asked about answering 'yes' to all items she said, "Because they did. Because preemies are real fussy. So they was telling me how to soothe her, you know, rub her head, just comfort her, talk to her."

It is not clear whether the intent of the question is to capture actual conversations between providers and new mothers or if the intent is to capture simply the idea that information was conveyed. Respondents did not always think specifically of conversations. Some included reading material they were given. One respondent marked 'yes' to almost every option but demonstrated uncertainty over the intent. She said, "Well, more or less. They gave me a packet with a lot of pages with all that information." Another respondent was also unsure whether reading material counted. She did decide to include it; however, she explained, "It wasn't so much of a conversation, it was more of a packet. It was more of a 'review this packet and if you have any questions about anything in particular [then ask]'...But it definitely wasn't a conversation." Another answered 'yes' to all items and explained, "They gave me a book...and everything was explained in there." Another respondent also included the conveyance of information that did not occur in an in-depth conversation. "A lot of it is on paper. They give it to you on paper and they kind of just skim through the things. It's not actually something where they sit for a long period of time and tell you everything in detail." Sometimes information was provided via video. One respondent said, "They have a video in which they explain all of this. I think this [the video] is targeted to first-time moms or moms with older babies who had forgotten this stuff."

Finally, some respondents had no clear memory of conversations related to these topics but answered 'yes' to various categories based on assumptions that these things were covered before leaving the hospital. One respondent first said, "I guess. I'm trying to think of what the nurses say." When asked if she would answer yes or no, she said, "Yeah – because the doctor comes in and looks at the baby and tells you if there's anything odd. I'm trying to remember." Another respondent answered 'yes' to items that seemed logical, even though she did not remember a specific conversation. She said, "The rest of those things are just standard information they give."

24. Were you and your baby discharged home from the hospital at the same time after the birth? Would you say _____?

- 1 No
- 2 Yes, you were discharged at the same time, and your baby went home with you
- 3 Yes, you were discharged at the same time, but your baby did not go home with you

Findings: Most respondents went home from the hospital the same time as their baby and had no difficulty understanding or answering the question. However, one respondent with a more complicated experience had some trouble answering. She raised two issues. First, she was unsure (at first) whether being at the hospital meant being a patient. She said, “Okay, that’s tricky. I was discharged before he was discharged because he needed to stay under the lights another day. But I was able to stay in the hospital with him, but not under care....I stayed over to be with him, but not as a patient.” As she thought about it she said, “So I guess the answer is no – we weren’t discharged at the same time.” The second issue she raised relates to social desirability. The nature of the questions led her to believe the overall intent was to assess her fitness as a mother. As a result, she became cautious in providing answers. She said:

If the questions about my child and everything was a separate set of questions, then it wouldn’t raise any alarms. But because you led with ‘have you had any history with drug abuse’, now I’m thinking you are seeing if I’m a fit parent. So I’m relating all of these questions to those questions. And if they aren’t related, it should be specified somewhere. Because I’m telling you, every question after that, that’s where my mind is going to. Like, no, I’m fit.

25. After being discharged from the hospital following birth, did your baby have to go back to the hospital and spend the night for any reason?

- 1 No
- 2 Yes

Findings: Most answered ‘no’ to this question and had no difficulty with the intent. For example, one respondent explained, “Once she came out [of the hospital], she was done. Just regular check-ups.” Most understood that the need to go back would be precipitated by health issues. One respondent explained, “Like if the baby had a fever. Because they actually told me that – that if the baby had a fever, I must take her to the ER.” Another said, “Like if the baby were to have trouble breathing, so I would have to take him to the ER.”

However, two problems did emerge. One respondent was confused about the phrase ‘following birth’. At first she said, “No...like the same day [as the hospital discharge]?” The interviewer repeated the question. “I guess not that day, but she HAS been back to the hospital.” She initially answered ‘no’ to this question even though her baby had been back to spend the night in the hospital on several separate occasions. Another respondent had difficulty deciding who the person of reference was in terms of the clause, ‘after being discharged’. Her first reaction was, “Can you repeat that?” After hearing the question a second time she was still unsure and said, “After she got discharged or after I got discharged? That’s what I’m trying to figure out...With her, once she got discharged from the hospital she didn’t have to go back.” Both respondents ultimately understood the intent, but had to talk through the question during probing in order to answer correctly.

26. Why did your baby have to go back to the hospital after being discharged? I’m going to read a list a reasons, for each one please tell me if it was a reason for your baby. Was it because of _____?

Reasons				
	No (1)	Yes (2)	Refused (8)	Don’t know (9)

a. Breathing problems				
b. Feeding difficulties				
c. Dehydration				
d. Surgery				
e. Injury				
f. Drug withdrawal				
g. Jaundice				
h. Fever				
i. Infection				
j. Audiology screening / rescreening				
k. Did they have to go back to the hospital for another reason?				
l. If YES, ask: What was it?				

Findings: This question was tested on only four respondents, as others were instructed to skip ahead. Findings are not conclusive, but suggest that it may not be easy to answer. For example, respondent knowledge may be imperfect, making it difficult to provide an answer with great certainty. One respondent answered ‘yes’ for infection but wasn’t sure. She said, “Yeah, I guess bronchiolitis is considered an infection...like the bronchial tubes were inflamed because of an upper respiratory infection.” Another debated injury but ultimately marked ‘no’. She said, “I don’t know what they call it, but some sort of blockage in the testicles.” Another respondent demonstrated the difficulty in making sense of the process of diagnosis and treatment. She said, “The first time when they were trying to figure it out – if she had a UTI [urinary tract infection] and they actually treated her for a UTI. They couldn’t figure out what it was.” The debate was over whether to mark yes or no for infection. She decided to mark ‘no’ because even though the baby was treated for an infection, it turned out she never actually had an infection.

One respondent for an interview conducted in Spanish was not able to select the answer option that applied to her situation. Her baby had to go back to the hospital after being discharged because he had high levels of bilirubin; however, rather than selecting item g (jaundice) the respondent answered k: “Other, bilirubin.” She added that she did not know what “'Ictericia' (jaundice)” was. The word for jaundice in Spanish could perhaps be clarified by adding in parentheses “amarilleo de la piel” (yellowing of the skin).

27. Is your baby living with you now? Would you say _____?

1	No, he or she is living with his or her biological father
2	No, he or she is living with another family member
3	No, he or she is in foster care
4	No, he or she has been adopted by someone else
5	No, he or she passed away
6	Yes

Findings: Every respondent accurately answered ‘yes’, so this question was not tested with regard to the other scenarios in the response options.

28. How old was your baby at his or her most recent health care visit or checkup?

Age in months _____

Findings: Respondents could generally answer this question, but most did not have an answer immediately available – they had to think about it. Most respondents used the recommended schedule for well-baby checkups and vaccines as their recall aid:

I'm thinking of the intervals where they do, like two months, four months, six months. And then is it eight months? Is it nine months? But it's somewhere in-between there.

Three months...four months! He got his four-month physical, I'm sorry.

She went and got her four-month shots.

That was his first set of vaccinations.

Yes, that checkup is due at 15 months so it was around that date.

Yes, it was the one where he received immunizations and medical checkup.

It was the one-year-old visit. He received immunizations and also they check that the head size was normal. They also check size and weight.

Only one respondent had difficulty with the question because she was confused over who the subject was – her or the baby. She first understood the question to be asking how old her baby was when she, herself, had her last checkup. “I thought you were asking about me...It is confusing because sometimes we are talking about me and sometimes we are talking about the baby.”

29. These next questions are about your baby’s behavior. For each one, please tell me if it applies to your baby. For each question, please say **Not at all** if your baby doesn’t do it, **Somewhat** if your baby does it sometimes, or **Very Much** if your baby does it all the time.

Actions					
	Not at all (1)	Somewhat (2)	Very Much (3)	Refused (8)	Don't know (9)
a. Does your baby have a hard time being with new people?					
b. Does your baby have a hard time in new places?					
c. Does your baby have a hard time with change?					
d. Does your baby mind being held by other people?					
e. Does your baby cry a lot?					
f. Does your baby have a hard time calming down?					
g. Is your baby fussy or irritable?					
h. Is it hard to comfort your baby?					
i. Is it hard to keep your baby on a schedule or routine?					

j. Is it hard to put your baby to sleep?					
k. Is it hard for you to get enough sleep because of your baby?					
l. Does your baby have trouble staying asleep?					

Findings: Respondents had several ways of approaching the intent of the questions in this series. First, some respondents took a relativistic perspective, assessing the extent to which these were either problem behaviors or behaviors that took place more or less often than that of other babies. A good example is one respondent who explained, “When I was thinking of these questions, I was thinking, ‘is it a problem?’ It’s not, except for when she’s sick.” As a result, she was inclined to answer ‘not at all’ to every item, not because the behavior never happened, but because it was not problematic or atypical. Another respondent explained, “She’s not a cranky baby at all...she cries, but not excessive.” For item g (fussy or irritable) one respondent said, “Somewhat, but not out of normal.” Others thought of the frequency of behavior in relation to other babies. One respondent said “Typical baby stuff. You know the way they behave.” For item e (cry a lot) another respondent answered ‘very much’ but added it was, “Just like any baby.”

Second, other respondents had a literal interpretation, assessing whether their child ever engaged in these behaviors at all, irrespective of whether it was a problem. For example, one respondent said, “It’s not always or not at all. Sometimes.” For item e (cry a lot) another respondent said, “I can’t say ‘not at all’ because she does [cry].” Another answered ‘somewhat’ to item j (hard to put baby to sleep) not because she deemed it a constant problem but because sometimes it is. She said, “I said ‘somewhat’ because sometimes she’s fighting sleep even though she’s tired. So instead of just going to sleep, she’ll throw a temper tantrum.” In general, respondents in this group were less likely to think of their baby’s behavior as a whole and more likely to think of specific scenarios under which their baby engaged in the behavior. Item a (hard time being with new people) is a good example. One respondent said, “I’m thinking of people she doesn’t see that often. Like strangers. She won’t go up to them. She has to warm up to them.” Another respondent had the same reaction, explaining that her baby’s behavior depends on the situation. She said, “It depends, so I guess somewhat.” When asked why it depends she said, “With ‘other people’ you have to be specific. Are they strangers?... Because she’s cool with her daycare people. She’s cool with some family members. [But] she takes a second to warm up [to people she doesn’t know].”

30. I’m going to read a list of things about your baby’s development. For each one, please tell me how much your baby is doing it right now. For each question, please say **Not Yet** if your baby is still not doing it, **Somewhat** if your baby does it sometimes, or **Very Much** if your baby does it all the time. If your baby doesn’t do something anymore, please tell us the option that describes how much he or she used to do it.

Actions	Not at all	Some-what	Very Much	Refused	Don’t know
	(1)	(2)	(3)	(8)	(9)
a. Holds up arms to be picked up					
b. Gets into a sitting position by him or herself					
c. Picks up food and eats it					
d. Pulls up to standing					
e. Plays games like “peek-a-boo” or “pat-a-cake”					
f. Calls parents “mama” or “dada” or similar name					

g. Looks around when people say things like “Where’s your bottle?” or “Where’s your blanket?”					
h. Copies sounds that other people make					
i. Walks across a room without help					
j. Follows directions like “Come here” or “Give me the ball”					

Findings: Most respondents approached this series of questions as related to their baby’s development. The following are examples of their comments during probing:

As far as all of the sensory things, as far as what they are supposed to be doing at that stage, I would say her development is pretty good. I haven’t had any warning signs or anything crazy happen.

I don’t have any concerns about his development. He’s a very busy little boy.

We have an appointment...to find out why we’re not walking...I just decided to take her back. The doctor was like, oh kids develop slower. I’m just noticing that she walks on her tippy-toes. I just want them to do another look.

Always, when we take the baby to the checkups, the doctor says he is doing very well. He is meeting all developmental goals for his age.

However, some respondents lost sight of the phrase ‘list of things about your baby’s development’ and answered on the basis of whether the baby had the will or motivation to engage in each behavior irrespective of ability to do so. For example, in the first item (raise arms to be picked up), one respondent answered ‘somewhat’ and explained her rationale. “When she done something bad, especially when she done spoiled that diaper, she’ll whine like she really wants to be picked up, but she know she did something wrong.” For b (sitting position), another respondent identified the difference between ability and motivation when she answered ‘somewhat’. She said, “Sometimes she will adjust herself and sometimes she will want you to do it for her.” Similarly, another respondent mentioned, “Sometimes she does it and sometimes she is uninterested.” For item g one respondent said, “We would ask ‘where’s the bottle?’ and she would act like she doesn’t know. She’ll take it, put it behind her back or under her blouse because she knows [her father] doesn’t want her to have it.” For j (follows directions) one respondent said, “You can call her and sometimes she can act like she doesn’t hear you. But she does.” One respondent also answered ‘somewhat’ and summed up her rationale well:

When she wants to. She’s very stubborn and she will ignore you. And she will look at you, so you know that she heard, but ‘I’m not coming right now because that’s not what I want to do’. But she can do it all the time if she wanted to. She ignores us a lot...[but] she CAN do it. It’s not something I’m concerned she’s unable to do.

It is unclear whether the question is attempting to capture ability or motivation to engage in the listed behaviors; however, this distinction is important in terms of assessing the extent to which a baby engages in the behavior.

31. *Since your baby was born, have you used any of the following services?* I’m going to read a list of services. For each one, please tell me if you have used any of the services *since your baby was born*.

Services				
	No (1)	Yes (2)	Refused (8)	Don’t know (9)
a. WIC				
b. SNAP				
c. Parenting groups				
d. Housing assistance				
e. Financial assistance				
f. Transportation assistance				
g. Emergency child care				

Findings: Respondents had no difficulty answering most of the items, but a few were cause for confusion. The most misunderstood item in this series was g (emergency child care). Respondents had different understandings. Some thought it referred to emergency medical care. When asked her understanding of the term, one respondent said, “In case an emergency comes up, to get the baby to the hospital.” Similarly, another explained, “Like go to the hospital or ER.” And another said, “Well, what I thought was that someone had to call 911.”

Others thought it referred to last-minute babysitting assistance. One respondent said she thought it meant “right then-and-there, I guess. Like you’re desperately needing someone to keep your child at that moment.” Another said, “I’m thinking in a childcare facility, like when you need it last minute.” One respondent said, “I heard about it two weeks ago. They were asking me if I was going to start working fulltime and I said that I couldn’t because I didn’t have a babysitter. And they told me the government can help you.”

One respondent thought it might refer to Child Protective Services. She asked, “Like CPS or something like that?” When asked what she thought she said, “It makes me think that the child had to be removed from the home for any reason. Which the answer would be no.”

Some respondents who answered ‘no’ admitted they did not know what should be included:

I am not sure what they mean by that. I think it’s asking if she had to go to the emergency room, but it feels like it doesn’t go with this question. I’m just going to answer no.

I’m not sure what they meant, really. Because who do you call for emergency child care? I don’t know. In the government, emergency services is Child Protective Services. So I don’t know. You can’t call and say, ‘I have to go to work...okay we’re going to send somebody over right now [to babysit].’ I don’t know what that question is.

That I don’t know. I don’t know nothing about no emergency child care. Never even heard about it.

Item c (parenting groups) was not consistently understood either. Some thought of formal classes. One respondent answered ‘yes’ and said, “I’ve been to parenting groups before. So it’s like a group of parents and

we talk about ways that we can discipline our kids without physical discipline.” Another answered ‘yes’ and said, “Like parenting classes and stuff like that. We do that as a group. It’s like we all learn from each other.” Another respondent who answered ‘yes’ explained, “I went through a little parenting group because they was giving away a pack-and-play thing for my baby. So we had to go through these little parenting classes to receive that.” One respondent answered ‘no’ and said she was thinking this included “going to a class with a group of parents and learning about the correct way that someone else feels that you should be parenting.” Another also answered ‘no’ and said these are groups designed “to help you. Some people have issues and some people are required to go to parenting groups, which is how to discipline your kid and things like that.”

Others thought of more informal networks of support, either in person or through social media. One respondent asked, “Well, parenting groups. Would that fall into online groups? Because we have online Facebook groups with parents.” She decided that should be included and answered ‘yes’. Another respondent also included a social media support group. She said, “There’s a group of moms that I belong to. We’re like a support group.” However, some respondents did not think social media counted. One respondent answered ‘no’ and said, “I had to think about parenting groups because I’ve done some online parenting groups. But it’s not like an organization, so I said no to that.”

Some respondents answered ‘no’ but were not at all certain how parenting groups should be defined. For example one asked, “Are those [groups] when parents have marriage problems?” Another respondent said, “I’m not sure if parenting groups is referring to programs that help you with breastfeeding, for example. I’m not sure if that is what this is referring to.”

Finally, item f was also potentially confusing. One respondent said, “I thought about transportation to and from school. You know, how they have buses that take them from the house to the school.” However, another respondent had a different understanding and said, “I think it’s when you have medical appointments or appointments at WIC and they pick you up.”

The following questions are about things you may have experienced in the *past 30 days*. In the *past 30 days*, please tell us how often the following statements were true:

32. “We worried whether our food would run out before we got money to buy more”.

Would you say that statement has been often true, sometimes true, or never true *in the past 30 days*?

- 1 Often true
- 2 Sometimes true
- 3 Never true

33. “The food that we bought just didn’t last, and we didn’t have money to get more.”

Would you say that statement has been often true, sometimes true, or never true *in the past 30 days*?

- 1 Often true
- 2 Sometimes true
- 3 Never true

Findings: Question 32 and 33 were often probed together. Respondents had no difficulty answering and seemed to provide genuine responses. Many respondents answered them both the same way. However, indications are that each question can function differently, with question 32 eliciting two different

interpretations, including both worries about food shortages (regardless of whether it happened or not) *and* actually experiencing food shortages. This is in contrast to question 33 which tended to capture only actual experiences with food shortages. For example, in question 32 some respondents reported in terms of their level of worry. One respondent said, “I would just worry. But that could be me just worrying.” Another respondent answered based on overall worry that she currently has about many things in relation to the death of her spouse. She said, “I am going through a very difficult time right now. My husband passed away...two months ago and I did not have a job. I am in a difficult situation worrying that I wouldn’t have the things I needed for my kids.” Another respondent also answered that although she sometimes worries, they have not gone without food. She said, “Sometimes things are tight, but we never go without. But there has been times when the budget was really tight.” Another respondent had a similar perspective. She answered ‘sometimes true’ and said, “It’s never been to the point where, oh my God, we can’t eat today...[but] we’re a family of five and I have a 13-year-old, so sometimes I’ve felt like it’s not enough.”

On the other hand, some respondents answered question 32 in relation to whether they literally experienced a shortage of food. For example, in explaining their answers, they would talk about their actual lack of food (not just worry about not having enough):

Yeah, sometimes food, it runs out. It’s just me and my four kids, but sometimes we eat more and sometimes we eat less.

It depends on what bills came in that need to be paid. And I’ve had to go through that. And quite a few times we wasn’t able to stretch the food.

I’ve ran out of milk because she drinks so much milk. That’s why I started putting cereal and stuff in her formula. Because she runs out. They [WIC] only give me nine cans [for the month].

These last questions are about things that could have happened or that you may have experienced *before you were 18 years of age*. We understand that some of these questions may be difficult, but your answers will help us understand some of the things people may experience when they are growing up.

34. When you were growing up, during the first 18 years of your life...

Questions				
	No (1)	Yes (2)	Refused (8)	Don’t know (9)
a. Were your parents <i>ever</i> separated or divorced?				
b. Was your mom less than 18 years old when she had you?				
c. Was your dad less than 18 years old when you were born?				
d. Did you live with anyone who was a problem drinker or alcoholic?				
e. Did you live with anyone who was depressed, mentally ill, or suicidal?				
f. Did you live with anyone who used illegal drugs or who abused prescription medications?				

g. Did you live with anyone who served time or was sentenced to serve time in a prison, jail, or other correctional facility?				
h. Did you frequently have to move houses or leave the places where you were living?				
i. Did you like going to school?				
j. Did you drop out of school before you were able to graduate?				
k. Were you ever bullied?				

Findings: The most difficult aspect of this series of questions was that some have a subjective component, requiring respondents to make judgments they feel unsure about or were not in a position to make. Item e (depressed/mentally ill) is an example. One respondent decided to answer ‘no’ but was not completely certain. She said, “As an adult, now I see that my parents aren’t okay. But...as a kid I didn’t [see it that way]. Now I’m an adult with experience and you start looking at your parents like people.” When asked whether she would answer ‘no’, she said, “Yeah, no. There wasn’t anything was like, psycho.”

Item d, (problem drinker/alcoholic) was fairly straightforward for some respondents. For example, one respondent answered ‘yes’ without question. She said, “I mean, I didn’t have such a good childhood due to the fact that my father is an alcoholic. This is the reason my parents separated. I moved out when I was 14 years old.”

However, this item was far more difficult for many respondents because it asked them to make an assessment they were either unsure about or simply reluctant to make. Several respondents expressed reluctance to make a judgment, but did answer ‘yes’ to the question. For example, one respondent chose ‘yes’ but showed hesitation in answering. When asked why, she said, “Because to me it wasn’t a problem. When I think of an alcoholic, I think of somebody who can’t function. Can’t maintain a household. She [her mother] drank a lot, but I always had what I needed. I was always clean; we always had food in the frig. But she did drink, so yes.” Another respondent who answered ‘yes’ said, “When I was young, the little I remember is that my dad would drink. He was not an alcoholic, but used to drink a lot.” Another respondent was also resistant to the term ‘alcoholic’ and said, “My father was not an alcoholic, but he did drink.” Another at first said, “My dad used to drink a lot, but he was not an alcoholic. So I don’t know.” When asked to explain, her response points to the stigma associated with the term ‘alcoholic’. She said, “My dad used to drink a lot. He still does – he’s still alive. My siblings drink a lot, too, but my dad is the one who does more. I don’t want to say he’s an alcoholic because he’s my dad. But he drinks a lot and I do think he has a problem, but it’s hard...”.

These responses suggest that some of the difficulty respondents were having may be due to the stigma associated with the term ‘alcoholic’. As a result, others answered ‘no’ even when their experiences suggested ‘yes’ might be the better answer. For example, one respondent answered ‘no’ but debated how to answer. She said, “My dad did drink, but not to the point where he couldn’t function or go to work. We have a family that drinks, let me put it like that [laughs].” When asked to explain more she said, “I do remember seeing my dad coming home drunk as a kid. It bothered me then, but that’s because I wasn’t an adult. Now, being an adult...drinking myself, I was like, oh, okay. I get it now.” When asked why she chose ‘no’ she explained, “It wasn’t to the point where he was drinking abusive or anything like that.” Another respondent described her experience, “My mom had a problem with alcohol here and there. Sometimes she would be drinking a lot and sometimes she’d stop. But after some time she’d drink again.” She goes on to explain why, even with this experience, she chose to answer ‘no’. “I’m not going to say she need rehab or she was an alcoholic per se.

But she drank a lot of beer. Maybe that's for the sake of not wanting to label her, but she drank a lot. Sometimes to the point where she could smell it through her pores."

Item h (frequently have to move) was also very subjective. Respondents were not consistent in their assessment of what constitutes 'frequently'. For example, one respondent who marked 'no' to this item explained, "Not frequent, but a couple times." During probing she described one moving experience. She said, "We actually moved out of state, like with no notice at all. The day I left was the day I found out I was leaving." When asked how many times she moved in total, she said nine times. This stands in contrast to another respondent who answered 'yes' to this question. When asked about her moving experiences, she moved only three times as a child. She said, "Originally I was in with my mom. When I was three I moved with my mother's sister. Then when I was, like four, I moved with my mother's brother. And I stayed there until I was 18." Note that between the ages of four and 18 she did not move at all.

Item k (ever bullied) was also subjective in the sense that what feels like or constitutes bullying may change over time. For example, several respondents marked 'no' to this item but talked about how the notion of bullying has changed. One respondent thought about her answer first. When asked why she said, "Because back in the day it was not considered bullying." The interviewer asked if she would answer, yes, she was bullied. "Perhaps. But that is how we would get along in our group. If I think about it now, it was bullying. But back then we didn't know what it was." Another respondent who also answered 'no' gave a similar rationale in terms of definitions changing over time. While she was bullied by today's standards, she did not see it that way as a child. She said, "Back in the day things were different or people were not easily offended." On the other hand, a respondent with a similar experience decided to answer 'yes', acknowledging how things change over time. When asked to explain she laughed and said, "I think everybody has suffered bullying sometime in their lives, because of their hair or any other thing that somebody makes fun of you for...things like that. But it was not as traumatic as it is now that children could be beaten, or that children cannot overcome a situation."

Finally, item a (parents ever separated/divorced) makes the false assumption that respondents' parents were married to begin with. This makes it difficult to answer when a respondent's parents never married. One respondent said, "They never separated. They just were never married." When pressed on how she would answer, she said 'no', although if filling it out on her own (she had the phone version), she would leave it blank. Another respondent did leave it blank. She questioned, "So, they weren't ever married...Were they ever separated or divorced? That's the question? I don't think that applies to me. I guess I'll just leave it blank."

APPENDIX: INSTRUMENT TESTED IN SPANISH

Las primeras preguntas son sobre usted y su salud.

1. Voy a leer un listado de condiciones. Para cada una, indique si usted la tiene actualmente. Usted tiene ____?

(PREGUNTA GUÍA: ¿Usted actualmente tiene _____?)

Condición	(No Leer)			
	No (1)	Sí (2)	Rechazó (8)	No sé (9)
f. Depresión				
g. Ansiedad				
h. Hepatitis B				
i. Hepatitis C				
j. Dolor crónico, que es dolor que dura más de 12 semanas o 3 meses				

2. **Desde que nació su bebé, ¿cuántas visitas de salud ha tenido usted con un médico, enfermera o proveedor de salud, incluyendo servicios dentales o de salud mental?** No incluya aquellas visitas al hogar que usted pueda haber tenido por un médico, enfermera o proveedor de salud.

(No Leer)

1 Número de visitas [_____]

2 No ha tenido visitas de salud desde que nació su bebé → Ir a la Pregunta 5

8 Rechazó

9 No sé/No Recuerdo

3. **¿Qué tipo de visita de salud ha tenido usted desde que nació su bebé?**

Tipo de visita	(No Leer)			
	No (1)	Sí (2)	Rechazó (8)	No sé (9)
l. Chequeo posparto				
m. Visita por problemas que estaba teniendo relacionados al parto o nacimiento de mi bebé				
n. Visita regular en la oficina de mi médico de familia o ginecólogo/obstetra				
o. Visita para una enfermedad o condición crónica				
p. Vista por una lesión				
q. Visita para planificación familiar o contraceptivos				
r. Visita por depresión o ansiedad				
s. Visita para una limpieza dental por un dentista o higienista dental				
t. Cuidado prenatal para un embarazo nuevo				
u. ¿Ha tenido otro tipo de visita?				
v. Si contestó "Sí", pregunte: ¿Qué tipo?				

4. Durante algunas de sus visitas de salud *desde que nació su bebé*, ¿algún médico, enfermera o profesional de la salud hizo algunas de las siguientes cosas?

	(No Leer)			
	No (1)	Sí (2)	Rechazó (8)	No sé (9)
e. Habló con usted sobre el manejo del dolor después del parto o nacimiento de tu bebé				
f. Le preguntó, en persona o en un formulario, si usted tomó bebidas alcohólicas				
g. Le preguntó, en persona o en un formulario, si usted fumó cigarrillos o utilizó otros productos de tabaco				
h. Le preguntó si se sentía triste o deprimida				

5. Voy a leer un listado de medicamentos recetados para el dolor. Para cada una, por favor dígame si usted lo ha utilizado *desde que nació su bebé*. Por favor incluya cualquier medicamento que usted pueda haber tomado para aliviar el dolor asociado al parto o al nacimiento de su bebé. ¿Usted utilizó _____ *desde que nació su bebé*?

Medicamentos recetados para el dolor	(No Leer)			
	No (1)	Sí (2)	Rechazó (8)	No sé (9)
i. Hidrocodona, como Vicodin®, Norco® o Lortab®				
j. Codeína, como Tylenol® #3 o #4, <u>no</u> es el Tylenol regular				
k. Oxidodona, como Percocet®, Percodan®, OxyContin® o Roxicodone®				
l. Tramadol, como Ultram® o Ultracet®				
m. Hidromorfona o meperidina, como Demerol®, Exalgo® o Dilaudid®				
n. Oximorfona, como Opana®				
o. Morfina, como MS Contin®, Avinza® o Kadian®				
p. Fentanilo, como Duragesic®, Fentora® o Actiq®				

ENTREVISTADORA: Si la mamá contestó "Sí" para alguna de las opciones en la Pregunta 5, continúe con la siguiente pregunta. Si no, ir a la Pregunta 7.

6. *Desde que nació su bebé*, ¿por cuantas semanas o meses usted ha utilizado medicamentos recetados para el dolor? Por favor, dígame el número total de semanas o meses que ha usado medicamentos recetados para el dolor *desde que nació su bebé*.

- (No Leer)
- 1 Número de semanas _____ (Rango: 1-45 semanas)
O
 2 Número de meses _____ (Rango: 1-10 meses)
- 3 Menos de una semana
- 8 Rechazó
- 9 No sé/No Recuerdo

7. Desde que nació su bebé, ¿con qué frecuencia ha usado los siguientes productos de tabaco? Voy a leer una lista de opciones. Para cada una, por favor, dígame **Todos los días** si ha usado ese producto de tabaco diariamente desde que nació su bebé, **Algunos días** si lo ha usado ocasionalmente desde que nació su bebé, o **Nunca** si no lo ha usado. ¿Tomó o usó _____?

(PREGUNTA GUÍA: ¿Diría que ha usado _____ todos los días, algunos días o nunca?)

Productos de tabaco	(No Leer)				
	Todos los días (1)	Algunos días (2)	Nunca (3)	Rechazó (8)	No sé (9)
e. E-cigarrillos u otros productos electrónicos de vaporización con nicotina					
f. Hookah					
g. Tabaco para mascar, tabaco sin humo, rapé					
h. Cigarros, puros o pequeños cigarros con filtros					

Las próximas preguntas son sobre cosas que pueden haber sucedido desde que nació su bebé.

8. Desde que nació su bebé, usted ha necesitado tratamiento o consejería para su uso de...

Substancias	(No Leer)			
	No (1)	Sí (2)	Rechazó (8)	No sé (9)
g. Medicamentos recetados para el dolor				
h. Drogas o medicamentos, sin incluir medicamentos recetados para el dolor				
i. Alcohol				
j. Cigarrillos u otros productos de tabaco				
k. ¿Necesitó tratamiento o consejería para otras sustancias?				
l. Si contestó "Sí", pregunte: ¿Para qué?				

ENTREVISTADORA: Si la mamá marcó "No" en todas las opciones en la Pregunta 8, pase a la pregunta 15. Si no, continúe con la siguiente pregunta.

9. Desde que nació su bebé, usted ha recibido tratamiento o consejería para su uso de...

Substancias	(No Leer)			
	No (1)	Sí (2)	Rechazó (8)	No sé (9)
h. Medicamentos recetados para el dolor				
i. Drogas o medicamentos, sin incluir medicamentos recetados para el dolor				
j. Alcohol				
k. Cigarrillos u otros productos de tabaco				
l. ¿Necesitó tratamiento o consejería para otras sustancias?				
m. Si contestó "Sí", pregunte: ¿Para qué?				

ENTREVISTADORA: Si la mamá ha recibido el tratamiento o consejería que necesitaba para su uso de cualquier sustancia, por favor pase a la Pregunta 11. Si la mamá no ha recibido todo el tratamiento o consejería que necesita, por favor continúe con la próxima pregunta.

10. Voy a leer una lista de razones por las cuales algunas personas pueden no recibir el tratamiento o consejería que necesitan para el uso de medicamentos, drogas, alcohol o productos de tabaco. Para cada una, por favor dígame si fue una razón para usted. ¿Fue porque _____?

Razones	(No Leer)			
	No (1)	Sí (2)	Rechazó (8)	No sé (9)
m. No pudo conseguir una cita o le colocaron en lista de espera				
n. Pudo reducir su uso o dejar de usar sin ayuda				
o. No pensó que necesitaba ayuda				
p. No tenía suficiente dinero o seguro para pagar los servicios				
q. No sabía a donde ir para recibir ayuda				
r. No tenía transportación				
s. No quería que las personas pensarán que usted tenía un problema				
t. Su compañero(a) no quería que recibiera ayuda				
u. Tenía miedo de perder custodia de su bebé o hijos				
v. Tenía demasiadas otras cosas pasando				
w. ¿Hubo otra razón?				
x. Si contestó "Sí", pregunte: ¿Cuál fue?				

ENTREVISTADORA: Si la mamá no recibió tratamiento o consejería pase a la Pregunta 15.

11. Desde que nació su bebé, ¿cuál de los siguientes tipos de tratamiento o consejería ha recibido? Voy a leer una lista de tipos de tratamiento o consejería. Para cada una, por favor dígame si la recibió. ¿recibió _____?

(PREGUNTA GUÍA: ¿Qué tipo de tratamiento o asesoramiento recibió?)

Tipos de tratamiento o consejería	(No Leer)			
	No (1)	Sí (2)	Rechazó (8)	No sé (9)
i. Consejería individual con un profesional de las ciencias de la conducta				
j. Consejería grupal con un profesional de las ciencias de la conducta				
k. Consejería con un miembro del clérigo u otro consejero religioso o de la comunidad				
l. Reuniones de auto-ayuda o de grupos de recuperación (como Alcohólicos Anónimos, <i>Self-Management and Recovery Training</i> (SMART), Manejo de Moderación (MM))				

m. Tratamiento asistido por medicamentos (conocido como MAT) que utiliza medicamentos como metadona, buprenorfina, Suboxone®, Subutex® o naltrexona (conocido también como Vivitrol®).				
n. Tratamiento o consejería para dejar de usar tabaco				
o. ¿Recibió algún otro tipo de tratamiento o consejería?				
p. Si contestó "SÍ", pregunte: ¿Qué tipo?				

12. Desde que nació su bebé, ¿dónde ha recibido tratamiento para su uso de medicamentos, drogas, o alcohol, no incluyendo cigarrillos? Voy a leer una lista de lugares. Para cada uno, por favor dígame si recibió tratamiento en ese lugar. ¿Fue en _____?

(PREGUNTA GUÍA: ¿Recibió tratamiento por el uso de medicamentos, drogas o alcohol en _____?)

Places	(No Leer)			
	No (1)	Sí (2)	Rechazó (8)	No sé (9)
j. Reuniones de grupos de auto ayuda				
k. Una oficina privada de un doctor				
l. La sala de emergencias				
m. El hospital donde me quedaba la noche				
n. Una facilidad de tratamiento donde no me quedaba por la noche				
o. Una facilidad de tratamiento residencial donde me quedaba la noche				
p. La cárcel o prisión				
q. ¿Recibió tratamiento en otro lugar?				
r. Si contestó "SÍ", pregunte: ¿Dónde?				

13. ¿Cuál fue el resultado del último tratamiento o consejería que recibió? ¿Usted diría que _____?

- 1 Todavía está en tratamiento → Ir a la Pregunta 15
- 2 Completó el tratamiento → Ir a la Pregunta 15
- o
- 3 No terminó el tratamiento

- (No Leer)** 8 Rechazó → Ir a la Pregunta 15
- 9 No sé/No Recuerdo → Ir a la Pregunta 15

14. ¿Cuáles fueron sus razones por las que no terminó tratamiento o consejería? Voy a leer una lista de razones. Para cada una, por favor dígame si fue una razón para usted. ¿Fue porque _____?

(PREGUNTA GUÍA: ¿Por qué no terminó su tratamiento o consejería?)

Razones	(No Leer)			
	No (1)	Sí (2)	Rechazó (8)	No sé (9)

f. Tuvo un problema con el programa				
g. No pudo continuar porque era muy costoso				
h. No tenía a nadie que le ayudara a cuidar a su bebé u otros hijos.				
i. Comenzó a usar medicamentos, drogas, alcohol u otras sustancias nuevamente.				
j. ¿Hubo otra razón?				
k. Si contestó "Sí", pregunte: ¿Cuál fue?				

Las siguientes preguntas son sobre el tiempo *después de que nació su bebé*.

15. Después de que nació su bebé, ¿alguien le sugirió que no amamantara o lactara a su nuevo bebé?

- (No Leer)
- | | | |
|---|-------------------|-----------------------|
| 1 | No | → Ir a la Pregunta 18 |
| 2 | Sí | |
| 8 | Rechazó | → Ir a la Pregunta 18 |
| 9 | No sé/No Recuerdo | → Ir a la Pregunta 18 |

16. ¿Quién le sugirió que no amamantara o lactara a su bebé? Voy a leer una lista de personas. Para cada una, dígame si esa persona le sugirió que no amamantara o lactara a su bebé. ¿Fue _____?

Personas	(No Leer)			
	No (1)	Sí (2)	Rechazó (8)	No sé (9)
i. El médico, la enfermera u otro profesional de la salud de su bebé				
j. Su médico, enfermera u otro profesional de la salud				
k. Su esposo o compañero → Ir a la Pregunta 18				
l. Su madre, padre, suegra o suegro → Ir a la Pregunta 18				
m. Otro miembro de su familia o pariente → Ir a la Pregunta 18				
n. Sus amigos → Ir a la Pregunta 18				
o. ¿Hubo otra persona que le recomendó que no amamantara o lactara?				
p. Si contestó "Sí", pregunte: ¿Quién?				

ENTREVISTADORA: Si un médico, enfermera u otro profesional de la salud le recomendó que no amamantara o lactara a su bebé, pase a la siguiente pregunta, de lo contrario, ir a la Pregunta 18.

17. ¿Por qué un médico, enfermera u otro profesional de la salud le sugirió que no amamantara o lactara a su bebé? Voy a leer una lista de razones. Para cada una, por favor dígame si fue una de las razones. ¿Fue porque _____?

Razones	(No Leer)			
	No (1)	Sí (2)	Rechazó (8)	No sé (9)

g. Tenía una condición médica que hacía que la lactancia materna fuera un problema para usted				
h. Tenía una condición médica que hacía que la lactancia fuera insegura para su bebé				
i. Había una preocupación de que las drogas o medicamentos que usted estaba utilizando pasaran a su bebé a través de su leche				
j. Su bebé tenía una condición médica y no se recomendaba que lo amamantara o lactara				
k. ¿Hubo otra razón?				
l. Si contestó "Sí", pregunte: ¿Cuál fue la razón?				

Las próximas preguntas son sobre la salud de su bebé *cuando era un recién nacido*.

18. Después de que nació su bebé, ¿un doctor, enfermera u otro profesional de la salud le dijo que su bebé tuvo abstinencia de drogas conocido como síndrome de abstinencia neonatal o síndrome de abstinencia de opioides neonatal?

(No Leer)

- 1 No
2 Sí

→ Ir a la Pregunta 21

- 8 Rechazó
9 No sé/No Recuerdo

→ Ir a la Pregunta 21

→ Ir a la Pregunta 21

19. ¿ Su bebé recibió algunos de los siguientes tipos de cuidado o tratamiento especial para ayudarlo con los síntomas de abstinencia de drogas? Voy a leer una lista de cuidados o tratamientos especiales. Para cada uno, por favor dígame si su bebé lo recibió. ¿Su bebé recibió _____?

Tratamientos	(No Leer)			
	No (1)	Sí (2)	Rechazó (8)	No sé (9)
j. Medicamentos como la morfina, metadona o buprenorfina				
k. Fluidos por vía intravenosa.				
l. Contacto piel a piel o cuidado canguro				
m. Dormir en una habitación tranquila y poco iluminada				
n. Fórmula alta en calorías				
o. Amamantamiento o lactancia				
p. Leche materna de una donante				
q. ¿Su bebé recibió otro tratamiento o servicio?				
r. Si contestó "Sí", pregunte: ¿Qué recibió su bebé?				

20. Voy a leer una lista de cosas que los médicos, las enfermeras o los profesionales de la salud pueden hacer después de que nazca su bebé. Para cada una, dígame si lo hicieron *después de que nació su bebé*, o no.

	(No Leer)			
	No (1)	Sí (2)	Rechazó (8)	No sé (9)
k. Le hablaron sobre por qué su bebé tuvo abstinencia de drogas				

l. Le hablaron sobre el tratamiento para bebés con abstinencia de drogas				
m. Le hablaron acerca de cuánto tiempo pueden durar los síntomas de abstinencia de su bebé				
n. Le hablaron sobre las cosas que su bebé podría experimentar				
o. Le hablaron sobre el comportamiento de su bebé				
p. Le hablaron de cuándo su bebé podría ir a la casa				
q. Le preguntaron acerca de los medicamentos que estaba tomando o tomó durante el embarazo.				
r. Le sugirieron que usted recibiera tratamiento o consejería para su uso de medicamentos, drogas o alcohol				
s. Le sugirieron que recibiera servicios para su bebé, como intervención temprana o programas de visitas domiciliarias				
t. Le hicieron una prueba de sangre o una prueba de puntuación para evaluar a su bebé para el síndrome de abstinencia neonatal				

21. Después de que nació su bebé, ¿cómo describiría dónde estuvo su bebé la mayor parte del tiempo durante su estadía en el hospital? ¿Se quedó _____ ?

- 1 Con usted en su habitación en el hospital, a veces conocido como "alojamiento"
- 2 En la sala de recién nacidos regular
- 3 En una sala de recién nacidos especializada para bebés que necesitan cuidados adicionales, como una sala de atención especial ("SCN") o una unidad de cuidados intensivos neonatales ("NICU")

(No Leer)

- 4 Su bebé no nació en el hospital
- 8 Rechazó
- 9 No sé/No Recuerdo

22. Antes de que le dieran el alta del hospital después de que nació su bebé, ¿pudo un médico, enfermera u otro profesional de la salud responder sus preguntas sobre la salud de su bebé?

- 1 No
- 2 Sí
- 3 Usted no tuvo preguntas sobre la salud de su bebé

(No Leer)

- 8 Rechazó
- 9 No sé/No Recuerdo

23. Voy a leer una lista de cosas sobre las cuales los médico, enfermera o profesional de la salud pudo hablar con usted. Para cada una, dígame si lo hicieron *antes de que le dieran el alta del hospital*.

	(No Leer)			
	No (1)	Sí (2)	Rechazó (8)	No sé (9)
j. Como calmar a su bebé				
k. Como responder a las necesidades de su bebé				
l. Sentir un apego con su bebé				

m. Dándole de comer a su bebé en la casa				
n. Tener un sitio seguro para que su bebé pueda dormir				
o. Teniendo a alguien que le ayude a cuidar a su bebé				
p. Llevar a su bebé a las visitas médicas con un doctor				
q. Manteniendo a su bebé seguro en su hogar				
r. Reconociendo las señales o síntomas en su bebé que requieren atención médica				

24. ¿Usted y su bebé fueron dados de alta del hospital a la misma vez después del nacimiento? ¿Usted diría que _____?

- 1 No
- 2 Sí, les dieron de alta a la misma vez y mi bebé vino a la casa con usted
- 3 Sí, les dieron de alta a la misma vez, pero mi bebé no vino con usted a la casa

- (No Leer)**
- 8 Rechazó
 - 9 No sé/No Recuerdo

25. Después de ser dado de alta cuando nació, ¿su bebé tuvo que regresar al hospital y pasar la noche por alguna razón?

- (No Leer)**
- 1 No → Ir a la Pregunta 27
 - 2 Sí

- 8 Rechazó → Ir a la Pregunta 27
- 9 No sé/No Recuerdo → Ir a la Pregunta 27

26. Después de ser dado de alta, ¿por qué su bebé tuvo que volver al hospital? Voy a leer una lista de razones, Para cada una, por favor, dígame si fue una razón para su bebé. ¿Fue a causa de _____?

(PREGUNTA GUÍA: Después de ser dado de alta, ¿ su bebé tuvo que regresar al hospital _____?)

Razones	(No Leer)			
	No (1)	Sí (2)	Rechazó (8)	No sé (9)
m. Problemas respirando				
n. Dificultades en alimentación				
o. Deshidratación				
p. Cirugía				
q. Una lesión				
r. Abstinencia de drogas				
s. Ictericia				
t. Fiebre				
u. Por una infección respiratoria o de otro tipo				
v. Para una evaluación o reevaluación de audiolgía				
w. ¿su bebé tuvo que ir al hospital por otra razón?				
x. Si contestó "SÍ", pregunte: ¿por qué?				

27. ¿Su bebé está viviendo con usted *actualmente*? ¿Usted diría _____?

- 1 No, él o ella está viviendo con su padre biológico → Ir a la Pregunta 31
- 2 No, él o ella está viviendo con otro miembro de la familia → Ir a la Pregunta 31
- 3 No, él o ella está siendo cuidado en un orfanato → Ir a la Pregunta 31
- 4 No, él o ella ha sido adoptado por otra persona → Ir a la Pregunta 31
- 5 No, él o ella falleció → Sentimos mucho su pérdida. Ir a la Pregunta 31
- 6 Sí

- (No Leer) 8 Rechazó → Ir a la Pregunta 31
- 9 No sé/No Recuerdo → Ir a la Pregunta 31

28. ¿Qué edad tenía su bebé la última vez que tuvo una visita de salud o chequeo?

- 1 Edad en meses [_____] [Rango: 0 – 10]

- (No Leer) 2 Su bebé nunca ha tenido una visita de salud o chequeo
- 8 Rechazó
- 9 No sé/No Recuerdo

29. Voy a leer una lista sobre el comportamiento de su bebé. Para cada una, por favor dígame si le aplica a su bebé. Para cada pregunta, diga **No** si no le aplica a su bebé, **A veces** si le aplica algunas veces, o **Frecuentemente** si le aplica a su bebé todo el tiempo.

Acciones	(No Leer)				
	No (1)	A veces (2)	Frecuentemente (3)	Rechazó (8)	No sé (9)
m. ¿Su bebé tiene dificultades estando con personas nuevas?					
n. ¿Su bebé tiene dificultades en lugares nuevos?					
o. ¿Su bebé tiene dificultades con cambios?					
p. ¿A su bebé le molesta ser cargado por otras personas?					
q. ¿Su bebé llora mucho?					
r. ¿A su bebé se le hace difícil tranquilizarse?					
s. ¿Su bebé es quisquilloso o irritable?					
t. ¿Es difícil consolar a su bebé?					
u. ¿Es difícil mantener a su bebé en un horario o rutina?					
v. ¿Es difícil dormir a su bebé?					
w. ¿Usted tiene dificultades durmiendo suficiente debido a su bebé?					
x. ¿Su bebé tiene problemas quedándose dormido?					

30. Voy a leer una lista de cosas sobre el desarrollo de su bebé. Para cada una, por favor dígame cuánto lo hace su bebé actualmente. Para cada pregunta, diga **Aún no** si su bebé aún no lo está haciendo, **Más o menos** si su bebé lo hace a

veces, o **Mucho** si su bebé lo hace todo el tiempo. Si su bebé ya no hace algo, por favor díganos la opción que describe cuánto solía hacerlo.

(PREGUNTA GUÍA: ¿Usted diría que su bebé aún no _____, lo hace más o menos, o lo hace mucho?)

Acciones	(No Leer)				
	Aún no (1)	Más o menos (2)	Mucho (3)	Rechazó (8)	No sé (9)
k. Sube sus manos para ser cargado					
l. Se pone en posición sentada por si solo					
m. Coge la comida y se la come					
n. Se levanta a la posición parada					
o. Participa en juegos como palmaditas y escondite					
p. Llama a sus padres "mamá" o "papá" o nombres similares					
q. Mira a su alrededor cuando alguien dice cosas como "¿Donde está tu biberón?" o "¿Donde está tu pañito?"					
r. Imita sonidos que hacen otras personas					
s. Camina a través de un cuarto sin ayuda					
t. Sigue instrucciones como "Ven aquí" o "Dame la bola"					

31. Desde que nació su bebé, ¿ha utilizado alguno de los siguientes servicios? Voy a leer una lista de servicios. Para cada una, dígame si ha utilizado alguno de los servicios desde que nació su bebé.

Servicios	(No Leer)			
	No (1)	Sí (2)	Rechazó (8)	No sé (9)
h. WIC				
i. SNAP				
j. Grupos de apoyo a padres				
k. Asistencia para vivienda				
l. Asistencia financiera				
m. Asistencia de transportación				
n. Cuidado para niños de emergencia				

Las siguientes preguntas son sobre cosas que usted puede haber experimentado en los pasados 30 días. En los últimos 30 días, díganos con qué frecuencia se cumplen las siguientes afirmaciones:

32. "Nos preocupábamos que se nos acabaría la comida antes de tener dinero para comprar más."
¿Usted diría que esto fue usualmente cierto, a veces cierto o nunca cierto en los últimos 30 días?

- 1 Usualmente cierto
- 2 A veces cierto
- 3 Nunca cierto

- (No Leer)**
- 8 Rechazó
 - 9 No sé/No Recuerdo

33. “La comida que compramos simplemente no duraba y no teníamos dinero para obtener más.” ¿Usted diría que esto fue usualmente cierto, a veces cierto o nunca cierto en los *últimos 30 días*?

- 1 Usualmente cierto
- 2 A veces cierto
- 3 Nunca cierto

- (No Leer)**
- 8 Rechazó
 - 9 No sé/No Recuerdo

Estas últimas preguntas son a cerca de cosas que pueden haber pasado o que usted puede haber experimentado antes de que tuviera 18 años de edad. Entendemos que algunas de estas preguntas pueden ser difíciles, pero sus contestaciones nos ayudarían a entender algunas de las cosas que las personas pueden experimentar cuando están creciendo.

34. Durante sus primeros 18 años de edad ...

Preguntas	(No Leer)			
	No (1)	Sí (2)	Rechazó (8)	No sé (9)
l. ¿Sus padres estuvieron divorciados o separados <i>en algún</i> momento?				
m. ¿Su mamá era menor de 18 años cuando le tuvo?				
n. ¿Su papá era menor de 18 años cuando nació?				
o. ¿Vivió con alguien que bebía mucho o era alcohólico?				
p. ¿Vivió con alguien que estaba deprimido, enfermo mental o suicida?				
q. ¿Vivió con alguien que usó drogas ilegales o que abusaba medicamentos recetados?				
r. ¿Vivió con alguien que cumplió una condena o fue condenado a cumplir una condena en una prisión, cárcel u otra institución correccional?				
s. ¿Tuvo que mudarse de casas o irse del lugar donde estaba viviendo frecuentemente?				
t. ¿Le gustaba ir a la escuela?				
u. ¿Dejó la escuela antes de poder graduarte?				
v. ¿Le hicieron <i>bullying</i> ?				