**Parental/Family INTERVIEW FORM**

### BEGINNING THE INTERVIEW

Interviewer Instructions:

The first 1 to 15 minutes of the home visit will usually be used to develop rapport with the parent, to thank her for allowing the visit, and to explain the program. Once a comfortable atmosphere has been achieved, the best way to begin the interview is to ask the mother or birthing person to describe in her own words how she and the child are doing since the delivery. The interviewer should call the child by his/her name, if given.

It is important to remain sensitive to the mother or birthing person’s need to expound on or digress from any particular event that generates strong feelings and to give her time to recall details and relate her experiences in her own words. The standardized questionnaire can follow when the mother or birthing person is able.

**“My name is (*Interviewer’s name*). I want to thank you for participating in the FIMR/HIV project to help us study systems of care for pregnant persons living with HIV and their families in our community so that we can work to improve the services you use and find additional ways to help families such as yours in the future.**

**This interview should take about 90 minutes. With your permission, I will take notes as we are talking because I want to capture all of your comments. Please don’t be distracted by this.**

**Before we start, I want to remind you that your participation today is voluntary and you may decline to answer any questions that you do not wish to answer or to end the interview at any time without any consequences to you or your family and that all information that identifies you, your family or your health care providers will be removed before the interview ques­tionnaire is reviewed. Also, there are no right or wrong answers in this discussion. We are interested in knowing what you think, so please feel free to be frank and to share your point of view. It is very important that we hear your story.**

**Do you have any questions about what I’ve just gone over? Let’s get started.”**

Data Collection Form: Auto populated

Site ID: Auto populated

Case ID: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Date of Interview: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Interviewer ID: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**How would you describe your relationship to [CHILD’S NAME]?**

The biological mother or birthing person

The foster/adoptive mother or birthing person

The guardian mother or birthing person

The childbearing biological parent

The non-childbearing biological parent

The partner of childbearing biological parent

How would you like to be referred to during this interview?

The mother

The birthing person

The biological parent

Other (specify):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**If the interviewee is not the parent who gave birth to the baby or would prefer to be referred to with a different title, make a note, and adjust the interview.**

**During the interview we use the terms breastfeeding and breastmilk. Are you comfortable with this language or do you prefer different terms?**

Okay with the term breastfeeding

Prefers the term chestfeeding

Prefers other term (specify):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**CHECK BOX APPROPRIATE BELOW IN THE CASE OF FETUS, INFANT OR CHILD DEATH**

**FETAL DEATH, STILLBIRTH OR NEONATAL DEATH IN THE HOSPITAL**

**INFANT OR CHILD DEATH AFTER DISCHARGE FROM HOSPITAL**

**IF NO BOX IS CHECKED, SKIP TO QUESTION 1 (BEFORE PART A)**

**IF THE CHILD IS NOT LIVING AT THE TIME OF INTERVIEW, ADJUST QUESTIONS ACCORDINGLY.**

**“We ask these questions to all families to improve services. Your answers mean a lot to us and can truly help us improve. However, we respect and understand your decision whether you choose to answer or decline questions, go at your own pace, or stop the interview at any given moment.”**

***(If a box is checked)* We’re so sorry for your loss. Many families have received referrals for grief counseling. Were you offered or provided grief counseling or other services as a result of your loss?**

0 = No

1 = Grief Counseling

2 = Referral for service before this interview

3 = Interview led to referral

4 = Referral needed

77 = Don’t know

98 = Decline to say

**Did you find these services helpful? Were there any additional services you found helpful?**

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77 = Don’t know

98 = Decline to say

**How have you been doing lately?**

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|  |

77 = Don’t know

98 = Decline to say

**IF A BOX IS CHECKED, SKIP TO PART A**

Question 1 = 1 text variable

**1. How are you and [CHILD’S NAME] doing since your delivery?**

Interviewer Instructions:

Listen while the mother or birthing person expands on this question, ask appropriate follow-up questions, and record as close as possible her response.

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77 = Don’t know

98 = Decline to say

### PART A: INFORMATION ON MOTHER OR BIRTHING PERSON

**“I would like to first start out by asking some questions about you. This will help us know more about you and your background.”**

1. **What is your age?**

**\_\_\_\_\_\_\_ Age**

98 = Decline to say

1. **Do you consider yourself**: *(Read and* s*elect only one*)

0 = Not Hispanic or Latino

1 = Hispanic or Latino

77 = Don’t know/Not sure

98 = Decline to say

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| 1. **Do you consider yourself:** *(Read and check all that apply)* | 0  No | 1  Yes | 77  Don’t Know | 98  Decline to say |
| American Indian or Alaska Native |  |  |  |  |
| Asian |  |  |  |  |
| Black or African American |  |  |  |  |
| Native Hawaiian or Other Pacific Islander |  |  |  |  |
| White |  |  |  |  |

1. **During most or all of your pregnancy, what was your marital status?** *(select only one****)***

1 = Single, not married

2 = Married

3 = Living as married (common law)

4 = Separated

5 = Divorced

6 = Widowed

7 = Domestic partner

76 = Other*(specify): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_*

77 = Don’t know

98 = Decline to say

1. **What is the highest level of schooling that you completed?** *(select only one)*

1 = No schooling

2 = Less than 8th grade

3 = Between 8th grade and 12th grade with no high school diploma

4 = High school graduate or GED

5 = Some college

6 = Technical school

7 = Associates Degree

8 = Bachelor’s degree

9 = Advanced college degree

77 = Don’t know

98 = Decline to say

1. **Where were you born?**

1 = Inside the continental United States (50 states), *(skip to A9)*

2 = Outside the United States

77 = Don’t know

98 = Decline to say

|  |
| --- |
| *IF “1= IN THE UNITED STATES”, SKIP TO A9* |

1. **In what country were you born?** \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

77 = Don’t know

98 = Decline to say

1. **About how old were you when you first moved to the US?**

\_\_\_\_\_ Age (Enter zero if less than 1 year old)

77 = Don’t know

98 = Decline to say

1. **What language do you speak most of the time at home?** *(Select only one)*

1 = English *(Skip to A11)*

2 = Spanish

3 = Creole

4 = French

5 = Italian

6 = Russian

7 = Polish

8 = Vietnamese

9 = Mandarin/Cantonese

76 =Other (*specify):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_*

77 = Don’t know

98 = Decline to say

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| --- |
| *IF “1 = ENGLISH”, SKIP TO A11* |

**“I’d like to ask you a few more questions about language and language services that you may have used”**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| 1. **Were interpretation or translation services offered to you during pregnancy at any of the following settings?** (*Read and check all that apply*) | 0  NO | 1  YES | 77  DON’T KNOW | 98  DECLINE TO SAY |
| During prenatal care |  |  |  |  |
| At an emergency room |  |  |  |  |
| At the hospital when you delivered |  |  |  |  |
| At the hospital **after** you delivered |  |  |  |  |
| At the pediatrician’s visit |  |  |  |  |
| At the family planning visit |  |  |  |  |
| At your HIV care visits |  |  |  |  |

“**Now I would like to ask you about how you paid for health care before, during and after you delivered.”**

| 1. **How did you pay for health care in the year before this pregnancy?** *Check all that apply* | 1. **How did you pay for health care during this pregnancy?** *Check all that apply* | 1. **How did you pay for health care since your delivery?** *Check all that apply* |
| --- | --- | --- |
| Private insurance | Private insurance | Private insurance |
| Medicaid | Medicaid | Medicaid |
| Medicare | Medicare | Medicare |
| Ryan White program | Ryan White program | Ryan White program |
| ADAP | ADAP | ADAP |
| CHAMPUS/Military insurance | CHAMPUS/Military insurance | CHAMPUS/Military insurance |
| Self-pay, but eligible for Medicaid | Self-pay, but eligible for Medicaid | Self-pay, but eligible for Medicaid |
| Self-pay | Self-pay | Self-pay |
| Other | Other | Other |
| Other (specify): | Other (specify): | Other (specify): |
| Did not receive care | Did not receive care | Did not receive care |
| Don’t know | Don’t know | Don’t know |
| Decline to say | Decline to say | Decline to say |

1. **Is there anything else about your background that you’d like to share with me or think I should know?**

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77 = Don’t know

98 = Decline to say

### PART B: INFORMATION ON MOTHER OR BIRTHING PERSON’S LIVING SITUATION

**“Now, I would like to ask about your living situation during your recent pregnancy. Think about your earnings, where you lived, your expenses, and any challenges you had financially.**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| 1. **During your pregnancy, did you…** *(Read list)* | 0  No | 1  Yes | 77  Don’t know | 98  Decline to say |
| Have stable housing? |  |  |  |  |
| Have trouble paying for food? |  |  |  |  |
| Worry about money and paying bills? |  |  |  |  |
| Have support to pay medical copays? |  |  |  |  |
| Have phone service available in your home? |  |  |  |  |

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| --- | --- | --- | --- | --- |
| 1. **During your pregnancy, did you stay for more than 24 hours in any of the following places?** *(Read and check all that apply)* | 0  No | 1  Yes | 77  Don’t know | 98  Decline to say |
| Hospital |  |  |  |  |
| Mental Health Center |  |  |  |  |
| Alcohol/Substance Use Treatment Center |  |  |  |  |
| Domestic violence shelter |  |  |  |  |
| Homeless or family shelter |  |  |  |  |
| Home for pregnant teens |  |  |  |  |
| Half-way house, group home |  |  |  |  |
| Correctional Facility (jail or prison) |  |  |  |  |
| Other |  |  |  |  |
| (*specify):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_* | | | | |
| None of these facilities *(skip to B5)* |  |  |  |  |

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| *IF B2 “NONE”, SKIP TO B5* |

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| --- | --- | --- | --- | --- |
| 1. **While you stayed there, did you get help with** *(read and check all that apply):* | 0  No | 1  Yes | 77  Don’t  Know | 98  Decline to  Say |
| Prenatal care |  |  |  |  |
| HIV care |  |  |  |  |
| General medical care |  |  |  |  |
| Assistance signing up for benefits/social work services |  |  |  |  |
| Mental health services |  |  |  |  |
| Peer support |  |  |  |  |
| Other |  |  |  |  |
| (Specify): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | | | |
| Did not receive help getting care *(Skip to B5)* |  |  |  |  |

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| *IF “Did not receive help getting care”, SKIP TO B5* |

1. **Please tell me BOTH the place and type of assistance received.**

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77 = Don’t know

98 = Decline to say

**“The next questions focus on persons that lived with you.”**

1. **During your pregnancy, not counting yourself, how many adults 18 years old and over lived with you?**

\_\_\_\_\_\_ Number of adults (Enter 0 if none)

77 = Don’t know

98 = Decline to say

1. **During your pregnancy, how many children < 18 years old, including those that may not be your own, lived with you?**

\_\_\_\_\_\_ Number of children (Enter 0 if none)

77 = Don’t know

98 = Decline to say

**“Now, let’s talk about changes you may have had in living situation.”**

1. **During your pregnancy and since delivery, how many times did you move?**

1 = None

2 = Once only

3 = 2 to 3 times

4 = 4 to 5 times

5 = More than 5 times

77 = Don’t know

98 = Decline to say

1. **At any time during your pregnancy, did you feel unsafe in the place where you were living?**

0 = No *(skip to B10)*

1 = Yes

77 = Don’t know *(skip to B10)*

98 = Decline to say *(skip to B10)*

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| --- |
| *IF “No”, “Don’t know” or “Decline to say”, SKIP TO B10* |

1. *(If yes)* **Please tell me a little more about it:**

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77 = Don’t know

98 = Decline to say

**“We recognize that these are difficult economic times and that people may have a hard time making ends meet.”**

1. **During your pregnancy or since your delivery, did you ever have trouble paying for housing-related costs, like your rent, mortgage, food, or basic utilities (phone, gas, water, electricity)?**

0 = No

1 = Yes

77 = Don’t know

98 = Decline to say

1. **Did you every worry about money before or during your pregnancy?**

0 = No

1 = Yes

77 = Don’t know

98 = Decline to say

1. **Is there anything else about your living situation that you’d like to share with me or think I should know?**

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77 = Don’t know

98 = Decline to say

### PART C: PRECONCEPTION HEALTH INFORMATION

**“Now, I want to start with asking you some questions about the time before the start of your most recent pregnancy.”**

| 1. **Were you ever told you had any health problems *before* you became pregnant?** *(Check all that apply. Prompt with examples if needed.)* | 0  No | 1  Yes | 77  Don’t know | 98  Decline to say |
| --- | --- | --- | --- | --- |
| Diabetes |  |  |  |  |
| Heart Disease/ Conditions |  |  |  |  |
| *(specify):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_* | | | | |
| High Blood Pressure |  |  |  |  |
| Seizures/Epilepsy |  |  |  |  |
| Depression or other mental health diagnosis |  |  |  |  |
| *(specify):* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | | | |
| Anemia |  |  |  |  |
| HIV |  |  |  |  |
| Cervical abnormalities\abnormal pap smear |  |  |  |  |
| Tooth Decay/Gum Disease |  |  |  |  |
| Cancer |  |  |  |  |
| *(specify):* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | | | |
| Hepatitis A |  |  |  |  |
| Hepatitis B |  |  |  |  |
| Hepatitis C |  |  |  |  |
| Sexually transmitted infection\* |  |  |  |  |
| *(specify):* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | | | |
| Other medical conditions |  |  |  |  |
| *(specify):* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | | | |
| None *(Skip to C3)* |  |  |  |  |

\*Such as, Chlamydia, Gonorrhea, Herpes, Syphilis

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| *IF “None”, GO TO C3* |

1. *(If yes)* ***Specify* the disease and what treatment was provided?**

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77 = Don’t know

98 = Decline to say

1. **In the year before this pregnancy, did a medical provider or nurse talk with you about contraception or family planning?**

0 = No

1 = Yes

77 = Don’t know

98 = Decline to say

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| --- | --- | --- | --- | --- |
| 1. **When you got pregnant this last time, what kind of birth control, if any, were you using?** *(Check all that apply)* | 0  No | 1  Yes | 77  Don’t know | 98  Decline to say |
| Pill |  |  |  |  |
| Diaphragm |  |  |  |  |
| Condom |  |  |  |  |
| Foam, Jelly, or Cream |  |  |  |  |
| Rhythm |  |  |  |  |
| Depo-Provera |  |  |  |  |
| Birth control implant |  |  |  |  |
| IUD (e.g. Minera, copper) |  |  |  |  |
| Withdrawal (Pulling Out) |  |  |  |  |
| Contraceptive patch |  |  |  |  |
| Contraceptive vaginal ring |  |  |  |  |
| Other |  |  |  |  |
| *(specify):* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | | | |
| None *(Answer C5)* |  |  |  |  |

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| *IF ANY C4 is = to ANY ITEM OTHER THAN “None”, Skip to C6* |

| 1. *(If None)* **What are the reasons that you not were using birth control right before you got pregnant this last time?***(Check all that apply)* | 0  No | 1  Yes | 77  Don’t know | 98  Decline to say |
| --- | --- | --- | --- | --- |
| Wanted to get pregnant |  |  |  | |
| Did not think she was going to sex |  |  |
| Did not think she could get pregnant |  |  |
| Did not like using birth control |  |  |
| Had trouble getting birth control |  |  |
| Was having side effects |  |  |
| Partner does not believe in or like using birth control or condoms |  |  |
| Financial issues (insurance co-pay too high, not covered) |  |  |
| Other |  |  |
| *(specify):* | | | | |

1. **How do you remember feeling about being pregnant?** (Read and select one)

1 = Wanted to get pregnant sooner

2 = Wanted to get pregnant later

3 = Wanted to be pregnant then

4 = Did not want to be pregnant then or at any time in the future

76 = Other*(specify):* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

77 = Don’t know

98 = Decline to say

1. **Is there anything else about your experiences or the care you received in the time just before your pregnancy that you’d like to share with me or think I should know?**

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77 = Don’t know

98 = Decline to say

### PART D: GENERAL PRENATAL CARE

**“In the next set of questions, I will ask you about the general prenatal care you received.”**

1. **How many weeks were you when you learned that you were pregnant?**

(*Interviewer: If participant provides months, convert months into weeks)*

\_\_\_\_\_\_\_\_\_ Weeks

77 = Don’t know

98 = Decline to say

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| 1. **During this pregnancy, other than a prenatal care provider, where else did you go for any health care you needed?** *(Check all that apply).* | 0  No | 1  Yes | 77  Don’t know | 98  Decline to say |
| Emergency room/urgent care |  |  |  |  |
| Labor and delivery unit at a different time *before* you were admitted to deliver |  |  |  |  |
| HIV specialist |  |  |  |  |
| Other |  |  |  |  |
| *(specify):* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | | | |
| Did not go elsewhere for care *(Skip to D4)* |  |  |  |  |

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| --- |
| *IF “DID NOT GO ELSEWHERE FOR CARE”, SKIP TO D4* |

1. **Why did you go to each of these places or providers?**

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77 = Don’t know

98 = Decline to say

1. **Did you receive any prenatal care from a medical provider, nurse-midwife, or nurse practitioner during this pregnancy?**

0 = No *(Skip to D11)*

1 = Yes

77 = Don’t know *(Skip to D11)*

98 = Decline to say *(Skip to D11)*

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| --- |
| *IF “No”, “Don’t know”, or “Decline to say”, SKIP TO D11* |

1. **How many weeks pregnant were you at your first visit for prenatal care?**

*(Interviewer: convert months to weeks. Don’t count a visit that was only for a pregnancy test, sonogram, or WIC appointment.)*

\_\_\_\_\_\_\_\_\_ Weeks

77 = Don’t know

98 = Decline to say

1. **Where did you go for your first prenatal visit or pregnancy check-up?**

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| --- |
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1. **Did you have to change your prenatal care provider during this pregnancy?**

0 = No *(Skip to D10)*

1 = Yes

77 = Don’t know *(Skip to D10)*

98 = Decline to say *(Skip to D10)*

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| --- |
| *IF “No”, “Don’t know”, or “Decline to say”, SKIP TO D10* |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| 1. *(If yes)* **Why did you have to change providers?** *(Check all that apply)* | 0  No | 1  Yes | 77  Don’t know | 98  Decline to say |
| Provider would not accept insurance |  |  |  |  |
| Could not pay for the visit or for the copay |  |  |  |  |
| Moved |  |  |  |  |
| Referred tospecialist |  |  |  |  |
| *(specify):*\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | | | |
| Other |  |  |  |  |
| *(specify):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_* | | | | |

1. **If you had to change prenatal care providers, where did you receive the rest of your prenatal care?**

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| 1. **When you received prenatal care during this pregnancy, did a medical provider, nurse or any other health worker talk to you about:** *(Read and check all that apply)* | 0  No | 1  Yes | 77  Don’t know | 98  Decline to say |
| --- | --- | --- | --- | --- |
| Medicines and drugs that could affect your pregnancy |  |  |  |  |
| Signs and symptoms of premature labor |  |  |  |  |
| Signs and symptoms that mean you should call the medical provider/hospital immediately |  |  |  |  |
| Fetal movement monitoring (kick counts) |  |  |  |  |
| Where to go in case of emergency |  |  |  |  |
| Environmental/work hazards |  |  |  |  |
| Avoiding smoking during pregnancy |  |  |  |  |
| Avoiding alcohol during pregnancy |  |  |  |  |
| Avoiding illegal drugs during pregnancy |  |  |  |  |
| Taking vitamins or iron during pregnancy |  |  |  |  |
| Benefits of your own dental care and hygiene |  |  |  |  |
| Getting tested for HIV (the virus that causes AIDS) |  |  |  |  |
| Getting tested for hepatitis C or getting the hepatitis vaccination |  |  |  |  |
| How to avoid getting or transmitting sexually transmitted diseases |  |  |  |  |
| What you should eat during your pregnancy |  |  |  |  |
| Benefits of getting exercise or physical activity during pregnancy |  |  |  |  |
| Vaccinations |  |  |  |  |
| Avoiding and reducing stress at home, work, school, etc. |  |  |  |  |
| Finding a medical provider or nurse practitioner to care for your baby |  |  |  |  |
| Choosing how to feed your baby |  |  |  |  |
| What to do if you were depressed |  |  |  |  |
| Family Planning |  |  |  |  |
| Importance of postpartum care |  |  |  |  |
| Safe Sleep/SIDS Risk Reduction Activities |  |  |  |  |
| Other |  |  |  |  |
| *(specify):* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | | | |

| 1. **Tell me about any challenges that you had in getting or in trying to get prenatal care?** *(Use prompts if needed. Check all that apply.)* | 0  No | 1  Yes | 77  Don’t know | 98  Decline to say |
| --- | --- | --- | --- | --- |
| Worried about pressure to have an HIV test |  |  |  |  |
| Worried about a drug test |  |  |  |  |
| Had alcohol or drug problem |  |  |  |  |
| Worried about being reported to child welfare agency |  |  |  |  |
| Had legal or criminal problems |  |  |  |  |
| Worried about legal/immigration status |  |  |  |  |
| Couldn’t get time off work or school |  |  |  |  |
| Couldn’t find a place in neighborhood to get medical care |  |  |  |  |
| Unable to get appointment (provider not available; fully booked) |  |  |  |  |
| Hours the clinic was open were inconvenient |  |  |  |  |
| Wait list/time to be seen was too long |  |  |  |  |
| Time with staff (medical provider or nurse) was too short |  |  |  |  |
| Staff doesn’t listen or act respectful |  |  |  |  |
| Appropriate translation/language services not available |  |  |  |  |
| Disliked or did not trust the staff |  |  |  |  |
| Did not have anyone to go with me or partner not available to go with me |  |  |  |  |
| Did not have childcare |  |  |  |  |
| Had no transportation or unreliable transportation |  |  |  |  |
| Did not have money or couldn’t afford the visit |  |  |  |  |
| Did not have insurance |  |  |  |  |
| Did not know where to go |  |  |  |  |
| No problems |  |  |  |  |
| Other |  |  |  |  |
| (*specify): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_* | | | | |

| 1. **What were the reasons you did not receive prenatal care?** *(Read and check all that apply)* | 0  No | 1  Yes | 77  Don’t know | 98  Decline to say |
| --- | --- | --- | --- | --- |
| Never had prenatal care with other pregnancies |  |  |  |  |
| Did not know she was pregnant |  |  |  |  |
| Did not plan to become pregnant |  |  |  |  |
| Did not want to become pregnant |  |  |  |  |
| Language barriers |  |  |  |  |
| Could not pay/limitations with health insurance coverage |  |  |  |  |
| No transportation |  |  |  |  |
| No childcare available |  |  |  |  |
| Could not get time off from work or school |  |  |  |  |
| Avoiding alcohol during pregnancy |  |  |  |  |
| Used alternative medicines |  |  |  |  |
| Did not need or want care |  |  |  |  |
| Other |  |  |  |  |
| (*specify:)\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_* | | | | |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| 1. **Were any of the following health problems identified *while* you were pregnant? (***Read and check all that apply)* | 0  No | 1  Yes | 77  Don’t know | 98  Decline to say |
| Diabetes |  |  |  |  |
| Heart Disease |  |  |  |  |
| High Blood Pressure |  |  |  |  |
| Anemia |  |  |  |  |
| Depression or other mental health diagnosis |  |  |  |  |
| *(specify):* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | | | |
| Tooth decay/Gum disease |  |  |  |  |
| Seizures/Epilepsy |  |  |  |  |
| Cancer |  |  |  |  |
| (specify): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | |  |  |
| Sexually Transmitted Diseases\* |  |  |  |  |
| *(specify):* | | | | |
| HIV |  |  |  |  |
| Hepatitis A |  |  |  |  |
| Hepatitis B |  |  |  |  |
| Hepatitis C |  |  |  |  |
| COVID-19 |  |  |  |  |
| Vaginal bleeding |  |  |  |  |
| *(specify):* | | | | |
| Other medical conditions |  |  |  |  |
| *(specify):* | | | | |
| I did not have any of these problems *(Skip to D18)* |  |  |  |  |

\*Such as, Chlamydia, Gonorrhea, Herpes, Syphilis

|  |
| --- |
| *IF “I did not have any of these problems”, GO TO D18* |

1. *(If yes)* **What was the disease or condition and what treatment was provided?**

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

*If* *NO to “DEPRESSION OR OTHER MENTAL HEALTH DIAGNOSIS” response in TABLE D13, GO TO D18*

“You answered yes when asked about depression or another mental health diagnosis when asked about problems identified during pregnancy. I’d like to learn a little more about that.”

1. (*If YES to DEPRESSION OR OTHER MENTAL HEALTH DIAGNOSIS)* **Did you receive any mental health services during your pregnancy?**

0 = No *(Skip to E17)*

1 = Yes *(Skip to E16)*

77 = Don’t know *(Skip to E18)*

98 = Refuse to say *(Skip to E18)*

1. *(If yes)* **What encouraged you to** **seek** **mental health support, such as a counseling session or group therapy or consider medication, during your pregnancy? (***Interviewer prompts: Did a provider or a case manager that you trust refer you?***)**

|  |
| --- |
|  |
|  |

1. *(If no)* **What prevented you from getting mental health support such as a counseling session or group therapy or consider medication, during your pregnancy?**

|  |
| --- |
|  |
|  |

1. **Is there anything else about your prenatal care and pregnancy that you’d like to share with me or think I should know?**

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

### PART E: HIV CARE BEFORE & DURING PREGNANCY

**“These next questions are about how you learned of your most recent HIV diagnosis, your HIV care before and during pregnancy and how your prenatal care and HIV care were related.”**

1. **When you first learned you were diagnosed with HIV, was it:** *(Read and check only one)*

1 = Before this pregnancy

2 = During this pregnancy, but before you went into labor

3 = At the time of your delivery

4 = After [CHILD’S NAME] birth

77 = Don’t know

98 = Decline to say

1. **Where did you first receive your HIV diagnosis?** *(Read and check only one)*

1 = Community health center

2 = HIV testing organization

3 = STD clinic

4 = Primary or general medical care clinic

5 = Family planning clinic

6 = County/local health department clinic

7 = Health fair

8 = Primary care provider’s office

9 = Prenatal care provider’s office

10 = Emergency room

11 = Over the counter test/home collection or at home test kit

11 = Indian health services/Tribal/Urban

12 = Managed Care Organization (MCO) or Health Maintenance Organization (HMO)

13 = Clinic in a hospital

14 = School or work-based clinic

15 = Correctional facility

76 = Other *(specify):* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

77 = Don’t know

98 = Decline to say

1. **How do you think you got HIV?** *(Check only one)*

1 = Having sex with someone with unknown HIV status

2 = Having sex with someone living with HIV

3= Having sex with someone living with HIV to try to get pregnant

4 = Using or sharing injection equipment

5 = Born with it

76 = Other *(specify):* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

77 = Don’t know

98 = Decline to say

|  |
| --- |
| ***IF E1 = “AT TIME OF DELIVERY” or “AFTER [CHILD’S NAME] BIRTH”, SKIP TO PART F*** |

1. **BEFORE or DURING your most recent pregnancy, did you receive medical care for HIV?**

0 = No, no medical care for HIV BEFORE pregnancy

1 = No, no medical care for HIV DURING pregnancy

2 = Yes, received medical care for HIV BEFORE pregnancy

3 = Yes, received medical care for HIV DURING pregnancy

77 = Don’t know

98 = Decline to say

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| 1. **What prevented you from receiving medical care for HIV BEFORE your pregnancy?** *Interviewer: Ask as an open-ended question and provide examples (Check all that apply)* | 0  No | 1  Yes | 77  Don’t know | 98  Decline to say |
| Not Applicable/Not diagnosed before pregnancy |  |  |  |  |
| Did not know where to go |  |  |  |  |
| Couldn’t afford it |  |  |  |  |
| Could not get there/No transportation |  |  |  |  |
| Could not get time off from work or school |  |  |  |  |
| Language barriers |  |  |  |  |
| Limitations of health insurance coverage |  |  |  |  |
| Could not get an appointment |  |  |  |  |
| No childcare |  |  |  |  |
| You didn’t feel well enough to go to the appointment(s) |  |  |  |  |
| Had too many other things to do (not a priority) |  |  |  |  |
| Going to care made you sad, depressed, anxious, upset |  |  |  |  |
| Having COVID-19, or being hospitalized due to COVID-19 |  |  |  |  |
| Other |  |  |  |  |
| *(specify):* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | | | |

Supplemental COVID section as an option for states

1. **DURING your most recent pregnancy, were you hospitalized with COVID-19?**

0 = No, was not hospitalized with COVID-19 DURING most recent pregnancy

1 = Yes, was hospitalized with COVID-19 DURING most recent pregnancy

77 = Don’t know

98 = Decline to say

|  |
| --- |
| *IF “No”, “Don’t know”, “Decline to say”, SKIP TO E11* |

1. **DURING your most recent pregnancy, in what trimester were you hospitalized with COVID-19?**

1 = 1ST Trimester

2 = 2nd Trimester

3 = 3rd Trimester

77 = Don’t know

98 = Decline to say

1. **How many doses of any COVID-19 vaccine have you received?**

0 = Have not received any COVID-19 vaccination

1 = One Dose

2 = Two Doses

3 = 3 or more doses (including boosters)

77 = Don’t know

98 = Decline to say

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| 1. **Did you experience any disruptions or significant changes due to illness or being hospitalized with COVID-19 DURING your most recent pregnancy?** *(Check all that apply. Don’t read choices.)* | 0  No | 1  Yes | 77  Don’t know | | 98  Decline to say |
| **DURING Pregnancy** | | | | | |
| Not Applicable |  |  |  |  | |
| School |  |  |  |  | |
| Employment |  |  |  |  | |
| Social Services (e.g. unemployment, TANF, WIC) |  |  |  |  | |
| Living environment |  |  |  |  | |
| HIV care |  |  |  |  | |
| Pregnancy care |  |  |  |  | |
| Mental health care |  |  |  |  | |
| Home-based services (non-child welfare) |  |  |  |  | |
| Child welfare services |  |  |  |  | |
| Other |  |  |  |  | |
| (Specify: *\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_)* | | | | | |

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| 1. **Please tell me about your access to pregnancy care due to COVID-19 DURING your most recent pregnancy?** *(Check all that apply. Don’t read choices.)* | 0  No | 1  Yes | 77  Don’t know | | 98  Decline to say |
| **DURING Pregnancy** | | | | | |
| Skipped or delayed or cancelled prenatal appointments |  |  |  |  | |
| Skipped or delayed routine HIV-related laboratory tests (e.g. CD4 and viral load test) |  |  |  |  | |
| Received any form of pregnancy care or services |  |  |  |  | |
| Accessed your medical provider for pregnancy care for an in-person appointment |  |  |  |  | |
| Accessed your medical provider for pregnancy care using a virtual video appointment |  |  |  |  | |
| Accessed your medical provider for pregnancy care using a telephone appointment |  |  |  |  | |
| Accessed your medical provider for pregnancy care using your clinic’s patient portal |  |  |  |  | |
| Other |  |  |  |  | |
| (Specify: *\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_)* | | | | | |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| 1. **What types of things prevented you from making it to your appointments to receive medical care for HIV DURING pregnancy?** Ask as open ended *(Check all that apply)* | 0  No | 1  Yes | 77  Don’t know | 98  Decline to say |
| Did not know where to go |  |  |  |  |
| Couldn’t afford it |  |  |  |  |
| Unable to use or access telemedicine |  |  |  |  |
| Could not get there/No transportation |  |  |  |  |
| Could not get time off from work or school |  |  |  |  |
| Language barriers |  |  |  |  |
| Limitations of health insurance coverage |  |  |  |  |
| Could not get an appointment |  |  |  |  |
| No childcare |  |  |  |  |
| You didn’t feel well enough to go to the appointment(s) |  |  |  |  |
| Had too many other things to do (not a priority) |  |  |  |  |
| Going to care made her sad, depressed, anxious, upset |  |  |  |  |
| Other |  |  |  |  |
| *(specify):* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | | | |

1. **In the year BEFORE your pregnancy, did you take medicine for HIV?**

0 = No

1 = Yes

77 = Don’t know

98 = Decline to say

Not applicable/Not diagnosed before pregnancy

1. **DURING your pregnancy, did you take medicine for HIV?**

0 = No

1 = Yes

77 = Don’t know

98 = Decline to say

|  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| 1. **Was there anything that prevented you from taking medicine for HIV BEFORE or DURING pregnancy?** *(Check all that apply)* | 0  No | 1  Yes | 77  Don’t know | 98  Decline to say | N/A | 0  No | 1  Yes | 77  Don’t know | 98  Decline to say | N/A |
| **BEFORE Pregnancy** | | | | | | **DURING Pregnancy** | | | | | |
| Was not going to a medical provider |  |  |  |  |  |  |  |  |  |  |
| Was not offered medicine |  |  |  |  |  |  |  |  |  |  |
| The clinic staff did not know you had HIV |  |  |  |  |  |  |  |  |  |  |
| Could not afford to pay for the medicine |  |  |  |  |  |  |  |  |  |  |
| Did not know you had HIV |  |  |  |  |  |  |  |  |  |  |
| Concern or fear about side effects |  |  |  |  |  |  |  |  |  |  |
| Declined the medicine |  |  |  |  |  |  |  |  |  |  |
| (specify): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | | | | | *(specify):\_*\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | | | | |
| Other |  |  |  |  |  |  |  |  |  |  |
| (specify): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | | | | | *(specify):\_*\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | | | | |

1. **BEFORE your pregnancy or DURING your pregnancy, do you recall having difficulties taking your medication exactly as prescribed?**

0 = No, no difficulties taking medications BEFORE pregnancy

2 = No, no difficulties taking medications DURING pregnancy

3 = Yes, difficulties taking medications BEFORE pregnancy

4= Yes, difficulties taking medications DURING pregnancy

77 = Don’t know

98 = Decline to say

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| 1. **People may miss taking their HIV medicines for a number of reasons. Please tell me about any challenges you recall experiencing with taking your medications before or during your pregnancy?** *(Check all that apply. Don’t read choices.)* | 0  No | 1  Yes | 77  Don’t know | | 98  Decline to say | 0  No | 1  Yes | 77  Don’t know | 98  Decline to say |
| **BEFORE Pregnancy** | | | | | | **DURING Pregnancy** | | | |
| Forgot to take them. |  |  |  |  | |  |  |  |  |
| Wanted to avoid side effects. |  |  |  |  | |  |  |  |  |
| Was busy with other things |  |  |  |  | |  |  |  |  |
| Had a change in daily routine |  |  |  |  | |  |  |  |  |
| Had problems taking pills at specified times (with meals, on an empty stomach, etc.) |  |  |  |  | |  |  |  |  |
| Couldn’t get to a medical provider or clinic |  |  |  |  | |  |  |  |  |
| Felt depressed or overwhelmed |  |  |  |  | |  |  |  |  |
| Did not think you needed HIV medicines |  |  |  |  | |  |  |  |  |
| Was on the street |  |  |  |  | |  |  |  |  |
| Had too many pills to take |  |  |  |  | |  |  |  |  |
| Couldn’t afford a refill |  |  |  |  | |  |  |  |  |
| Other |  |  |  |  | |  |  |  |  |
| (*Specify*): *\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_* | | | | | | (*Specify*): *\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_* | | | |

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| 1. **BEFORE or DURING your pregnancy, were you given information about? *(****Read list and check all that apply****)*** | 0  No | 1  Yes | 77  Don’t know | 98  Decline to say | 0  No | 1  Yes | 77  Don’t know | 98  Decline to say |
| **BEFORE Pregnancy** | | | | | **DURING Pregnancy** | | | |
| Using condoms to avoid spreading HIV to a sexual partner |  |  |  |  |  |  |  |  |
| Importance of HIV medicines for your own health |  |  |  |  |  |  |  |  |
| Medicines that you could take to help protect your baby from getting HIV |  |  |  |  |  |  |  |  |
| The importance of taking the correct amount of medication and when to take it |  |  |  |  |  |  |  |  |
| Tests, suchasCD4 and viral load tests, to monitor your health |  |  |  |  |  |  |  |  |
| Taking medication called PrEP to help prevent you from getting HIV |  |  |  |  |  |  |  |  |
| Other |  |  |  |  |  |  |  |  |
| *(specify):* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | | | | *(specify):* \_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | | |
| None |  |  |  |  |  |  |  |  |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| 1. **BEFORE or DURING your pregnancy, did you attend any of the following?** *(Check all that apply)* | 0  No | 1  Yes | 77  Don’t know | 98  Decline to say |
| Classes specifically for persons living with HIV |  |  |  |  |
| Classes for pregnant persons living with HIV |  |  |  |  |
| Support group for persons living with HIV |  |  |  |  |
| None |  |  |  |  |

1. **DURING your pregnancy, was the HIV care site located at a different address or facility than your prenatal care?**

0 = No

1 = Yes

77 = Don’t know

98 = Decline to say

99 Did not receive prenatal care

1. **Was the prenatal provider the same person that you saw for HIV care?**

0 = No

1 = Yes

77 = Don’t know

98 = Decline to say

99 Did not receive prenatal care

1. **What else can you tell me about your HIV care during your most recent pregnancy that you’d like to share with me or think I should know?**

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

### PART F: NUTRITION AND OTHER HEALTH HABITS

**“In this section, I’ll ask you about your nutrition and overall health habits during your pregnancy.”**

1. **Did your prenatal care provider talk to you about nutrition and weight gain during pregnancy?**

0 = No

1 = Yes discussed, gained too much weight

2 = Yes discussed, gained too little weight

3 = Yes discussed, gained appropriate amount

77 = Don’t know

98 = Decline to say

1. **During your pregnancy, were you receiving services from WIC?**

0 = No

1 = Yes

77 = Don’t know

98 = Decline to say

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| 1. **Where there any barriers or difficulties in getting WIC services?**   *(Check all that apply)* | 0  No | 1  Yes | 77  Don’t  Know | 98  Decline  to say |
| Did not need assistance |  |  |  |  |
| Did not qualify |  |  |  |  |
| Did not know how or where to access services |  |  |  |  |
| There was a long waiting list |  |  |  |  |
| Difficulty requesting formula |  |  |  |  |
| Concerns about confidentiality |  |  |  |  |
| Other reason |  |  |  |  |
| (*specify):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_* | | |  |  |

|  |
| --- |
| *IF* ***F2*** *IS NOT EQUAL TO “No”, “Don’t know” or “Decline to say”, SKIP TO F5* |

| 1. **Which of the following services did the WIC office provide?** *(Check all that apply)* | 0  No | 1  Yes | 77  Don’t know | 98  Decline to say |
| --- | --- | --- | --- | --- |
| Referrals for prenatal care |  |  |  |  |
| Other health care referral |  |  |  |  |
| Information about whether or not to breastfeed |  |  |  |  |
| Information about formula feeding |  |  |  |  |
| Food supplements |  |  |  |  |
| Testing for HIV |  |  |  |  |
| Information about HIV |  |  |  |  |
| Referrals for HIV testing or HIV care |  |  |  |  |
| Other |  |  |  |  |
| (*specify):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_* | | | | |
| No services/information given |  |  |  |  |

“**The next questions are similar to the ones I previously asked you, but focus on after your delivery.”**

1. **Since your delivery, are you receiving WIC services?**

0 = No *(skip to F8)*

1 = Yes

77 = Don’t know *(skip to F8)*

98 = Decline to say *(skip to F8)*

|  |
| --- |
| *IF “No”, “Don’t know”, “Decline to say”, SKIP TO F8* |

1. (If yes) **Has WIC provided formula or food for your baby?**

0 = No

1 = Yes

77 = Don’t know

98 = Decline to say

99 Does not apply; mother or birthing person does not have custody of baby

1. **Since your delivery, has/does WIC provide food for you?**

0 = No

1 = Yes

77 = Don’t know

98 = Decline to say

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| 1. **During pregnancy or since your delivery, have you had challenges getting enough or appropriate food for yourself?** (Check all that apply) | 0  No | 1  Yes | 77  DON’T  KNOW | 98  DECLINE TO SAY |
| No *(Skip to F10)* |  |  |  |  |
| Yes, during pregnancy |  |  |  |  |
| Yes, since delivery |  |  |  |  |

|  |
| --- |
| *IF “No”, “Don’t know”, “Decline to say”, SKIP TO F10* |

1. *(If yes)* **Please tell me a bit more about the challenges and how you dealt with them:**

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

1. **Since your delivery, have you had challenges getting enough formula or food for your baby?**

0 = No *(Skip to F12)*

1 = Yes

77 = Don’t know *(Skip to F12)*

98 = Decline to say *(Skip to F12)*

99 Does not apply; mother or birthing person does not have custody of baby *(Skip to F18)*

|  |
| --- |
| *IF “No”, “Don’t know”, “Decline to say”, SKIP TO F12* |

1. (If yes) **please tell me a bit more about the challenges:**

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

1. **Did [CHILD’S NAME] ever receive breastmilk?**

0 = No *(Skip to F16)*

1 = Yes

77 = Don’t know *(Skip to F16)*

98 = Decline to say *(Skip to F16)*

1. (If yes) **Where did the breastmilk come from?**

1 = You breastfed

2 = The breastmilk was donated from a friend or private source

3 = From a milk/lactation bank

77 = Don’t know

98 = Decline to say

1. **For how long did [CHILD’S NAME] receive breastmilk?**

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| 1. **What were the reasons why [CHILD’S NAME] received breastmilk?** (*Check all that apply*) | 0  No | 1  Yes | 77  Don’t know | 98  Decline to say |
| Medical provider or nurse encouraged breastfeeding |  |  |  |  |
| Really wanted to breastfeed my baby |  |  |  |  |
| Had a plan for breastfeeding developed with my medical provider |  |  |  |  |
| Did not have formula or enough formula |  |  |  |  |
| Feared that others would ask why I wasn’t breastfeeding |  |  |  |  |
| Feared that not breastfeeding would reveal my HIV status |  |  |  |  |
| Did not know I had HIV |  |  |  |  |
| Thought that breastfeeding was good for the baby |  |  |  |  |
| I was taking medicines to prevent HIV |  |  |  |  |
| The baby was taking medicines to prevent HIV |  |  |  |  |
| I had an undetectable viral load |  |  |  |  |
| Other |  |  |  |  |
| (*specify):* | | | | |

1. **Sometimes people chew food and then give it to their baby. Has anyone ever pre-chewed food or medicine for [CHILD’S NAME]?**

0 = No *(Skip to F18)*

1 = Yes

77 = Don’t know *(Skip to F18)*

98 = Decline to say *(Skip to F18)*

99 Does not apply; mother or birthing person does not have custody of baby *(Skip to F18)*

|  |
| --- |
| *IF “No”, “Don’t know”, “Decline to say”, or “Does not apply” SKIP TO F18* |

1. *(If yes)* **Please tell me a bit more about when and how often you’ve done this.**

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

1. **Has anyone else ever pre-chewed food or medicine for [CHILD’S NAME]?**

0 = No

1 = Yes

77 = Don’t know

98 = Decline to say

**Many parents tell us that pregnancy is a stressful time, and that they may turn to smoking, alcohol, and drug use to cope with stress or anxiety. Please remember that all your answers will be kept private, and that this information will not be reported with your name.”**

1. **In the last 3 months of your pregnancy, did you smoke tobacco cigarettes?**

0 = No

1 = Yes, average number of cigarettes/day?\_\_\_\_\_\_\_ (20 cigarettes in one pack)

77 = Don’t know

98 = Decline to say

1. **In the last 3 months of your pregnancy, did you use electronic cigarettes?**

0 = No

1 = Yes, average number of e-cigarettes/day? (assume that one time consists of around 15 puffs or lasts around 10 minutes)

77 = Don’t know

98 = Decline to say

1. **In the last 3 months of your pregnancy, how many alcoholic drinks did you have in an average week?** (Select one)

Never (skip to F25)

Monthly or less

2 to 4 times a month

2 to 3 times a week

4 or more times a week

77 = Don’t know

98 = Decline to say

1. **Did you ever receive any alcohol treatment services or professional help to reduce alcohol use during any of the following time periods?** (check all that apply)

0 = No, no alcohol treatment or professional help received *(skip to F25)*

1 = During the year prior to this pregnancy

2 = During pregnancy

3 = Since delivery

77 = Don’t know *(skip to F25)*

98 = Refuse to say *(skip to F25)*

1. **What were the reasons that you received alcohol treatment?**

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

1. **Where there any barriers to getting alcohol treatment during your pregnancy?**

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

| 1. **Now we’re going to ask about other medications not related to HIV. During your pregnancy, did you take any of the following prescription or other over-the-counter medications?**  *(Read and check all that apply)* | 0  No | 1  Yes | 77  Don’t know | 98  Decline to say |
| --- | --- | --- | --- | --- |
| Vitamins |  |  |  |  |
| Diet pills |  |  |  |  |
| Sleeping pills or tranquilizers |  |  |  |  |
| (*specify*):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | | | |
| Antidepressants or mood regulators |  |  |  |  |
| (*specify*): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | | | |
| Demerol, Morphine |  |  |  |  |
| (*specify*): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | | | |
| Pain killers |  |  |  |  |
| (s*pecify*):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | | | |
| Steroids |  |  |  |  |
| (*specify*):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | | | |
| Antibiotics |  |  |  |  |
| *(specify):*\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | | | |
| Anti-seizure |  |  |  |  |
| *(specify):*\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | | | |
| Hormones |  |  |  |  |
| *(specify):*\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | | | |
| Allergy medications |  |  |  |  |
| *(specify):* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | | | |
| Any other medications |  |  |  |  |
| *(specify):* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | | | |

**“Now, I am going to ask you a few questions about drugs used for recreational or other reasons. Some people tell us that they use drugs because they feel stressed about their pregnancy or because they want to relax or feel good.** **Remember all your answers are private and will not be reported with your name.”**

| 1. **During your pregnancy, which drugs did you use?** *(Read and check all that apply)* | 0  No | 1  Yes | 77  Don’t know | 98  Decline to say |
| --- | --- | --- | --- | --- |
| Marijuana, edibles or hashish |  |  |  |  |
| Benzodiazepine |  |  |  |  |
| Opiates |  |  |  |  |
| Fentanyl |  |  |  |  |
| Crack |  |  |  |  |
| Cocaine |  |  |  |  |
| Crystal meth (methamphetamine) |  |  |  |  |
| Heroin |  |  |  |  |
| PCP, angel dust, LSD |  |  |  |  |
| Speed/Uppers |  |  |  |  |
| Methadone |  |  |  |  |
| Drug used but type unknown |  |  |  |  |
| Other |  |  |  |  |
| *(specify):*\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ |  |  |  |  |
| None |  |  |  |  |

1. **During your pregnancy, how often did you inject non-prescribed drugs?**

1 = Not at all (Skip to F30)

2 = More than once a day

3 =Once a day

4= More than once a week

5 = Once a week or less

77 = Don’t know

98 = Decline to say

1. **Did you ever receive any drug treatment services or professional help to reduce drug use during any of the following time periods?**

0 = No, no alcohol treatment or professional help received (skip to F31)

1 = During the year prior to this pregnancy

2 = During pregnancy

3 = Since delivery

77 = Don’t know (skip to F31)

98 = Refuse to say (skip to F31)

1. **What were the reasons that you received drug treatment?**

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

1. **Where there any barriers to getting drug treatment during your pregnancy?**

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

1. **What else can you tell me about your nutrition, smoking, alcohol, or drug use that you’d like to share with me or think I should know?**

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

### PART G: DELIVERY OF BABY

**“I now want to ask you some questions about the delivery of [CHILD’S NAME].”**

1. **What kind of delivery plan did you discuss with your provider?** *(Interviewer prompts:**Where to go? Who to call? What type of delivery? Bringing medication.**Were you comfortable with the plan? Did you feel involved in the decision making? Were there any last minute changes e.g. delivered in a different hospital? )*

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

1. **Did you deliver [CHILD’S NAME] in a hospital?**

0 = No

1 = Yes *(Skip to G4)*

77 = Don’t know *(Skip to G4)*

98 = Decline to say *(Skip to G4)*

|  |
| --- |
| *IF G1 IS NOT EQUAL TO “NO”, SKIP TO G4* |

1. *(If no)* **Where did you deliver [CHILD’S NAME]?**

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

|  |
| --- |
| *IF G2 is “No”, SKIP TO G9 after G3.* |

1. **Did you deliver at the hospital where you planned to deliver, or did you deliver at a different hospital?**

0 = Delivered at the intended hospital

1 = Delivered at a different hospital than planned

77 = Don’t know

98 = Decline to say

1. **Did you feel supported during the labor and delivery process?** *(Interviewer prompts: Confidentiality concerns were addressed; Able to have a support person in the room or virtually).*

0 = No

1 = Yes (Skip to G7)

77 = Don’t know

98 = Decline to say

1. **If no, can you tell me a little more?**

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

1. **Did your labor and delivery go as you thought it would?**

0 = No

1 = Yes (Skip to G7)

77 = Don’t know

98 = Decline to say

1. **If no, can you tell me a little more?**

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

1. **Did** **you have trouble getting to the hospital?**

0 = No *(Skip to G11)*

1 = Yes

77 = Don’t know *(Skip to G11)*

98 = Decline to say *(Skip to G11)*

|  |
| --- |
| *IF “No”, “Don’t know”, “Decline to say”, SKIP TO G11* |

1. *(If yes)* **Tell me about the trouble you had.**

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

1. **When you were admitted to the hospital to give birth, were you tested for HIV?**

0 = No

1 = Yes

77 = Don’t know

98 = Decline to say

1. **Did you tell/disclose your HIV status to the hospital staff?***(check all that apply)*

0 = No

1 = Yes

77 = Don’t know

98 = Decline to say

1. **Can you tell me more about your reasons to disclose or not to disclose?**

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

**CHECK BOX BELOW IF FETAL DEATH, STILL BIRTH OR NEONATAL DEATH IN THE HOSPITAL AND SKIP TO G18**

**FETAL DEATH, STILL BIRTH OR NEONATAL DEATH IN THE HOSPITAL**

**“The next questions are about information provided by a medical provider, nurse or any other health worker after your delivery when in the hospital.”**

| 1. **Did they talk to you about...? (***Read and check all that apply***)** | 0  NO | 1  YES | 77  DON’T KNOW | 98  DECLINE TO SAY |
| --- | --- | --- | --- | --- |
| How to give your baby HIV medication |  |  |  |  |
| Not breastfeeding to avoid HIV transmission to your baby |  |  |  |  |
| Post-partum depression/baby blues |  |  |  |  |
| Suppressing lactation and caring for your breasts |  |  |  |  |
| HIV care for yourself |  |  |  |  |
| Contraception and family planning |  |  |  |  |
| The importance of taking the baby to the medical provider to get care |  |  |  |  |
| The importance of taking the baby to the medical provider for HIV testing |  |  |  |  |
| The importance of keeping postpartum care appointments |  |  |  |  |
| Maternal signs and symptoms that warrant medical attention |  |  |  |  |
| Infant signs and symptoms that warrant medical attention |  |  |  |  |
| Where to go in case of a maternal or infant emergency |  |  |  |  |
| General infant care, bathing, feeding, safe sleep, infant safety, car seats, etc. |  |  |  |  |
| Nothing was discussed |  |  |  |  |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| 1. **Before you left the hospital, did someone help you make follow-up appointments for** (read and select all that apply): | 0  No | 1  Yes | 77  DON’T  KNOW | 98  DECLINE TO SAY |
| Your follow-up HIV care |  |  |  |  |
| [CHILD’S NAME] Pediatric care |  |  |  |  |
| Your post-partum gyn care |  |  |  |  |

1. **Did [CHILD’S NAME] attend the follow-up appointment within 14 days after leaving the hospital to check weight and general health?**

0 = No

1 = Yes *(Skip to G18)*

77 = Don’t know *(Skip to G18)*

98 = Decline to say *(Skip to G18)*

|  |
| --- |
| *IF G16 is “Yes”, “Don’t know”, “Decline to say”, SKIP TO G18* |

1. *(If no)***What prevented [CHILD’S NAME] from receiving a follow-up appointment within the first two weeks?**

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

1. **Did you go to a postpartum GYN care appointment?**

0 = No

1 = Yes *(Skip to G20)*

77 = Don’t know *(Skip to G20)*

98 = Decline to say *(Skip to G20)*

|  |
| --- |
| *IF G18 “Yes”, “Don’t know”, “Decline to say”, SKIP TO G20* |

1. *(If no)* **What prevented you from receiving a postpartum care appointment**?

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

1. **Did you go to an HIV follow-up appointment?**

0 = No

1 = Yes *(Skip to G22)*

77 = Don’t know *(Skip to G22)*

98 = Decline to say *(Skip to G22)*

1. *(If no)* **What prevented you from getting to the appointment**?

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

1. **What else can you tell me about the delivery of your baby or that you’d like to share with me or think I should know?**

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

### PART H: OTHER CHILDREN

**“In this section, I’ll ask you about your other children.”**

1. **Not counting your most recent pregnancy, how many other children do you have?**

**Number of children** *(Enter 0 if none and Skip to Part J)*

77 = Don’t know

98 = Decline to say

|  |
| --- |
| *IF “0”, SKIP TO PART I* |

**“These next questions are about the HIV status of your other children.”**

1. **Have all your other children been tested for HIV?**

0 = No

1 = Not all my children

2 = Yes *(Skip to H4)*

77 = Don’t know *(Skip to H4)*

98 = Decline to say *(Skip to H4)*

|  |
| --- |
| *IF “Yes”, “Don’t know”, “Decline to say”, SKIP TO H4* |

1. *(If No or Not all children)* **What prevented them from being tested for HIV?**

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

|  |
| --- |
| *IF H2 is “0=No”, Skip to interviewer instructions and H5* |

1. **Have any of your other children been diagnosed with HIV?**

0 = No

1 = Yes

77 = Don’t know

98 = Decline to say

Instructions to the interviewer:

Provide resources for HIV testing of other children at the end of the interview.

1. **What else would you like to share about your other children?**

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

### PART I: POSTPARTUM REPRODUCTIVE HEALTH

**CHECK BOX BELOW IF PATIENT IS UNABLE TO HAVE FUTURE CHILDREN AND SKIP TO PART J**

**NO LONGER ABLE TO HAVE CHILDREN**

**“Now I want to ask you about your current or future pregnancy intentions.”**

1. **Do you want to get pregnant again any time in the future?**

0 = No *(Skip to I3)*

1 = Yes

77 = Don’t know

98 = Decline to say

|  |
| --- |
| *IF “No”, SKIP TO I3* |

1. **By when would you like to get pregnant?**

1 = Immediately, already trying

2 = Within 1 year

3 = Between 1-2 years

4 = In 2 or more years

77 = Don’t know

98 = Decline to say

1. **Since you were diagnosed with HIV, has a health care provider (physician, nurse, counselor, etc.) ever spoken with you about how to safely have children if you want them?**

0 = No

1 = Yes

77 = Don’t know

98 = Decline to say

1. **Since your delivery, has a health care provider (physician, nurse, counselor, etc.) ever talked to you about birth control (i.e., contraception) or family planning?**

0 = No

1 = Yes

77 = Don’t know

98 = Decline to say

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| 1. **Since you delivered, what are all the different methods of birth control (i.e., contraception) that you have used or are currently using?** *(Check all that apply)* | 0  No | 1  Yes | 2  Currently  Using | 77  Don’t know | 98  Decline to say |
| Male condoms |  |  |  |  |  |
| The “pill” (oral contraceptive) |  |  |  |  |  |
| Diaphragm |  |  |  |  |  |
| Hormonal Intrauterine devices “IUD” |  |  |  |  |  |
| Non-hormonal Intrauterine devices “IUD” |  |  |  |  |  |
| Injection (Depo-Provera) |  |  |  |  |  |
| “Morning after pill” |  |  |  |  |  |
| Rhythm method |  |  |  |  |  |
| Withdrawal |  |  |  |  |  |
| Female condom |  |  |  |  |  |
| Implant (Implanon) |  |  |  |  |  |
| Contraceptive cream |  |  |  |  |  |
| Contraceptive patch |  |  |  |  |  |
| Contraceptive vaginal ring |  |  |  |  |  |
| Contraceptive sponge or foam |  |  |  |  |  |
| My partner has had a vasectomy (male sterilization) |  |  |  |  |  |
| Other |  |  |  |  |  |
| (*specify*): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | | | | |
| None *(see interviewer instructions)* |  |  |  |  |  |
| None, currently pregnant |  |  |  |  |  |

Instructions to the interviewer:

Provide resources on family planning at the end of the interview.

1. **What else can you tell me about your feelings toward and plans for future pregnancy?**

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

### PART J: INFORMATION ON NON-CHILDBEARING BIOLOGICAL PARENT and CURRENT PARTNER

**“The questions in this section will help us learn more about [CHILD’S NAME]’s non-childbearing biological parent and his background. By biological, I mean the person who fathered your baby. Later I’ll ask about any other partners.”**

**“These first few questions are about your relationship with the non-childbearing biological parent.”**

1. **How would you describe your relationship with the non-childbearing biological parent during your pregnancy and right now?** *(Read and select only one)*

|  |  |
| --- | --- |
| **During Pregnancy**  1 = Non-existent (had no contact with him)  2 = Not good at all  3 = Poor  4 = Fair  5 = Good  6 = Excellent  77 = Don’t know  98 = Decline to say | **Now (at time of interview)**  1 = Non-existent (had no contact with him)  2 = Not good at all  3 = Poor  4 = Fair  5 = Good  6 = Excellent  77 = Don’t know  98 = Decline to say |

1. **Do you know the HIV status of your baby’s non-childbearing biological parent? (Select one)**

0 = No *(skip to J4)*

1 = Yes, living with HIV

2 = Yes, not living with HIV

77 = Don’t know *(skip to J4)*

98 = Decline to say *(skip to J4)*

|  |
| --- |
| *IF “No”, “Don’t Know”,” Decline to say”, SKIP TO J4* |

1. **When did the baby’s non-childbearing biological parent disclose his status to you?**

0 = Status never disclosed

1 = Prior to the pregnancy

2 = During the pregnancy

3 = After the pregnancy

77 = Don’t know

98 = Decline to say

*IF J2 is “Yes, HIV-positive”, Skip to J5*

“There is a daily medication that can be taken by someone who does not have HIV that can reduce their risk of getting HIV if they are exposed to HIV. This medicine is call PrEP.”

1. **Have you and your non-childbearing biological parent talked to anyone, such as a medical provider or community health worker, about your partner taking PrEP?**

0 = No

1 = Yes

77 = Don’t know

98 = Decline to say

1. **Is the baby’s non-childbearing biological parent your current partner?**

0 = No

1 = Yes *(Skip to J7)*

2 = Don’t have a current partner *(Skip to J7)*

77 = Don’t know

98 = Decline to say

1. **Do you know your current partner’s HIV Status?**

0 = No

1 = Yes

77 = Don’t know

98 = Decline to say

Not applicable; does not have a current partner

“There is a daily medication that can be taken by someone who does not have HIV that can reduce their risk of getting HIV if they are exposed to HIV. This medicine is call PrEP.”

1. **Have you and your partner talked to anyone, such as a medical provider or community health worker, about your partner taking PrEP?**

0 = No

1 = Yes

2 = NA/Partner living with HIV

77 = Don’t know

98 = Decline to say

1. **Is there anything else you would like to share or tell me about your baby’s non-childbearing biological parent or your current partner (if applicable)?**

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

### PART K: HIV DISCLOSURE

**“Some people may find it difficult to tell family, friends or loved ones that they have HIV. I would like hear about your experience.”**

1. **Have you told anyone that you have HIV?**

0 = No *(Skip to K4)*

1 = Yes

77 = Don’t know *(Skip to K4)*

98 = Decline to say *(Skip to K4)*

|  |
| --- |
| *IF “No”, “Don’t Know”,” Decline to say”, SKIP TO K4* |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| 1. *(If yes)* **Did you tell… that you have HIV?** *(Read and check all that apply)* | 0  No | 1  Yes | 77  Don’t know | 98  Decline to say |
| Family members |  |  |  |  |
| Friends |  |  |  |  |
| A sexual partner who is not the non-childbearing biological parent |  |  |  |  |
| The non-childbearing biological parent |  |  |  |  |
| Employer or people that you work with |  |  |  |  |
| Other |  |  |  |  |
| (*specify*): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | | | |

1. **After you told others that you have HIV, did you get any support from them?**

0 = No

1 = Yes

77 = Don’t know

98 = Decline to say

1. **Have you had any negative experiences after others learned that you have HIV?**

0 = No *(Skip to K6)*

1 = Yes

77 = Don’t know *(Skip to K6)*

98 = Decline to say *(Skip to K6)*

|  |
| --- |
| *IF “No”, “Don’t know”, Decline to say”, SKIP TO K6* |

1. **If yes, what negative experiences did you have after others learned that you had HIV?**

|  |
| --- |
|  |
|  |

98 = Decline to say

1. **Do all of your health care providers know that you have HIV?**

0 = No

1 = Yes *(Skip to K8)*

77 = Don’t know

98 = Decline to say

|  |
| --- |
| *IF “Yes”, SKIP TO Interviewer Instructions and K8* |

1. *(If no)* **What are the reasons that these providers do not know that you have HIV?**

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

Instructions to the interviewer:

Say: “At the end of the interview, if you like, I can talk with you more about how we can help you disclose your status.”

After completion of the interview discuss referral to PCRS.

1. **Is there anything else about telling others about your HIV status that you’d like to share with me or think I should know?**

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

### PART L: SOCIAL SERVICES

**“Now, I have some questions about social services. I will read a list of services to you. Please tell me whether you have used any of these services.”**

Instructions to the interviewer:

Offer appropriate and available referrals at the end of the interview.

|  | 1. **Did you use \_\_\_\_\_\_ services during your pregnancy or since delivery?** | 1. **Was this service helpful?** | 1. **Would you have liked to have used \_\_\_\_\_\_?** |
| --- | --- | --- | --- |
| Social work or case management | 0 = No *(Go to L3)*  1 = Yes  77 = Don’t know  98 = Decline to say | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say  *(Skip L3)* | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say |
| Assistance with registering for Medicaid or health insurance | 0 = No *(Go to L3)*  1 = Yes*)*  77 = Don’t know  98 = Decline to say | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say  *(Skip L3)* | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say |
| Home medical visits | 0 = No *(Go to L3)*  1 = Yes  77 = Don’t know  98 = Decline to say | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say  *(Skip L3)* | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say |
| Non-medical home visits | 0 = No *(Go to L3)*  1 = Yes  77 = Don’t know  98 = Decline to say | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say  *(Skip L3)* | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say |
| Dental care | 0 = No *(Go to L3)*  1 = Yes  77 = Don’t know  98 = Decline to say | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say  *(Skip L3)* | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say |
| Financial assistance | 0 = No *(Go to L3)*  1 = Yes  77 = Don’t know  98 = Decline to say | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say  *(Skip L3)* | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say |
| Unemployment/job training services | 0 = No *(Go to L3)*  1 = Yes  77 = Don’t know  98 = Decline to say | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say  *(Skip L3)* | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say |
| Help paying for HIV medicines | 0 = No *(Go to L3)*  1 = Yes  77 = Don’t know  98 = Decline to say | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say  *(Skip L3)* | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say |
| Help with remembering to take HIV medicines as prescribed | 0 = No *(Go to L3)*  1 = Yes*)*  77 = Don’t know  98 = Decline to say | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say  *(Skip L3)* | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say |
| Mental Health services (e.g., counseling) | 0 = No *(Go to L3)*  1 = Yes  77 = Don’t know  98 = Decline to say | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say  *(Skip L3)* | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say |
| Infant and pediatric mental health | 0 = No *(Go to L3)*  1 = Yes  77 = Don’t know  98 = Decline to say | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say  *(Skip L3)* | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say |
| Substance use treatment and recovery services | 0 = No *(Go to L3)*  1 = Yes  77 = Don’t know  98 = Decline to say | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say  *(Skip L3)* | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say |
| Education program (e.g., GED) | 0 = No *(Go to L3)*  1 = Yes  77 = Don’t know  98 = Decline to say | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say  *(Skip L3)* | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say |
| Child care | 0 = No *(Go to L3)*  1 = Yes  77 = Don’t know  98 = Decline to say | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say  *(Skip L3)* | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say |
| Transportation | 0 = No *(Go to L3)*  1 = Yes*)*  77 = Don’t know  98 = Decline to say | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say  *(Skip L3)* | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say |
| Food assistance | 0 = No *(Go to L3)*  1 = Yes  77 = Don’t know  98 = Decline to say | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say  *(Skip L3)* | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say |
| WIC | 0 = No *(Go to L3)*  1 = Yes  77 = Don’t know  98 = Decline to say | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say  *(Skip L3)* | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say |
| Lactation suppression support | 0 = No *(Go to L3)*  1 = Yes  77 = Don’t know  98 = Decline to say | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say  *(Skip L3)* | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say |
| Housing (including shelters) | 0 = No *(Go to L3)*  1 = Yes  77 = Don’t know  98 = Decline to say | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say  *(Skip L3)* | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say |
| Other | 0 = No *(Go to L3)*  1 = Yes  77 = Don’t know  98 = Decline to say | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say  *(Skip L3)* | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say |
| *Specify:* |  |  |  |

|  | 1. **Did your child receive any of the following services** | 1. **Was this service helpful?** | 1. **Would you have liked to have used \_\_\_\_\_\_?** |
| --- | --- | --- | --- |
| Pediatric social work or case management | 0 = No *(Go to L6)*  1 = Yes  77 = Don’t know  98 = Decline to say | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say  *(Skip L6)* | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say |
| Assistance with registering for Medicaid or health insurance | 0 = No *(Skip L6)*  1 = Yes*)*  77 = Don’t know  98 = Decline to say | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say  *(Skip L6)* | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say |
| Home medical visits | 0 = No *(Go to L6)*  1 = Yes  77 = Don’t know  98 = Decline to say | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say  *(Skip L6)* | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say |
| Non-medical home visits | 0 = No *(Go to L6)*  1 = Yes  77 = Don’t know  98 = Decline to say | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say  *(Skip L6)* | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say |
| Help paying for HIV medicines | 0 = No *(Go to L6)*  1 = Yes  77 = Don’t know  98 = Decline to say | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say  *(Skip L6)* | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say |
| Help with giving HIV med as prescribed | 0 = No *(Go to L3)*  1 = Yes*)*  77 = Don’t know  98 = Decline to say | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say  *(Skip L6)* | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say |
| Infant and pediatric mental health | 0 = No *(Go to L3)*  1 = Yes  77 = Don’t know  98 = Decline to say | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say  *(Skip L6)* | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say |
| Child care | 0 = No *(Go to L6)*  1 = Yes  77 = Don’t know  98 = Decline to say | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say  *(Skip L6)* | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say |
| Transportation for well-baby and HIV care visits | 0 = No *(Go to L6)*  1 = Yes*)*  77 = Don’t know  98 = Decline to say | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say  *(Skip L6)* | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say |
| Infant feeding support e.g. formula, other | 0 = No *(Go to L6)*  1 = Yes  77 = Don’t know  98 = Decline to say | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say  *(Skip L6)* | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say |
| WIC | 0 = No *(Go to L6)*  1 = Yes  77 = Don’t know  98 = Decline to say | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say  *(Skip L6)* | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say |
| Lactation suppression support | 0 = No *(Go to L6)*  1 = Yes  77 = Don’t know  98 = Decline to say | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say  *(Skip L6)* | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say |
| Safe sleep | 0 = No *(Go to L6)*  1 = Yes  77 = Don’t know  98 = Decline to say | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say  *(Skip L6)* | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say |
| Other | 0 = No *(Go to L6)*  1 = Yes  77 = Don’t know  98 = Decline to say | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say  *(Skip L6)* | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say |
| *Specify:* |  |  |  |

1. **Is there anything else about social services that you’d like to share with me or think I should know?**

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

### PART M: MATERNAL POST-DELIVERY CARE AND HIV MEDICATION

**“Now I am going to ask you some questions about your medical care since your delivery.”**

1. **Since your delivery, have you had any unexpected medical conditions that required attention from a health provider?**

0 = No *(Skip to M3)*

1 = Yes

77 = Don’t know *(Skip to M3)*

98 = Decline to say *(Skip to M3)*

|  |
| --- |
| *IF “No”, “Don’t know”, “Decline to say”, SKIP TO M3* |

1. (If yes) **Tell me more about what happened?**

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

1. **Are you currently receiving health care to help manage your HIV?**

0 = No

1 = Yes *(Skip to M5)*

77 = Don’t know *(Skip to M5)*

98 = Decline to say *(Skip to M5)*

|  |
| --- |
| *IF “Yes”, “Don’t know”, “Decline to say”, SKIP TO M5* |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| 1. (If no) **What are the reasons that you are not receiving health care to help manage your HIV?** *(Check all that apply)* | 0  No | 1  Yes | 77  Don’t know | 98  Decline to say |
| Have no transportation or unreliable transportation |  |  |  |  |
| Have no money or insurance |  |  |  |  |
| Have no one to watch your children |  |  |  |  |
| Doesn’t know where to go |  |  |  |  |
| Has no free time |  |  |  |  |
| Can’t get an appointment |  |  |  |  |
| The wait is too long when you do have an appointment |  |  |  |  |
| The staff or provider doesn’t listen to you |  |  |  |  |
| No one on staff or provider speaks your language |  |  |  |  |
| Doesn’t like or trust the staff or provider |  |  |  |  |
| Difficulty finding a new provider after pregnancy (needed a referral) |  |  |  |  |
| Changed provider after pregnancy (e.g., caused confusion, delayed care/appts) |  |  |  |  |
| You and baby had different providers |  |  |  |  |
| Could not get a medical provider or nurse to take her as a patient |  |  |  |  |
| Doesn’t need or want care |  |  |  |  |
| Doesn’t think it helps her |  |  |  |  |
| Doesn’t want to take medicine |  |  |  |  |
| Other |  |  |  |  |
| (*specify*): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | | | |

1. **Have you ever taken HIV medicines since delivery?**

0 = No (*Skip to M9)*

1 = Yes

77 = Don’t know *(Skip to M9)*

98 = Decline to say *(Skip to M9)*

**M5b. Are you currently taking medicine for HIV?**

0 = No (*Skip to M7)*

1 = Yes

77 = Don’t know *(Skip to M7)*

98 = Decline to say *(Skip to M7)*

|  |
| --- |
| *IF “No”, “Don’t know”, “Decline to say”, SKIP TO M7* |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| 1. **”Thinking about HIV medications prescribed to you by your medical provider(s), please answer the following questions. In the past 30 days…”** *(Read and check all that apply)* | 0  No | 1  Yes | 77  Don’t know | 98  Decline to say |
| Did you ever forget to take your HIV medications? |  |  |  | |
| Did you have trouble obtaining HIV medications? |  |  |
| Did you sometimes stop taking your HIV medications? |  |  |
| Did you stop or skip taking them because you didn’t like how they made you feel? |  |  |

**“A lot of people with new babies have trouble taking medications or forgetting to take them.”**

1. **Have you had any problems taking HIV medications since delivery?**

0 = No *(Skip to M10)*

1 = Yes

77 = Don’t know *(Skip to M10)*

98 = Decline to say *(Skip to M10)*

|  |
| --- |
| *IF “No”, “Don’t know”, “Decline to say”, SKIP TO M10* |

1. **Did you talk to a health care provider about these problems?**

0 = No *(Skip to M10)*

1 = Yes

77 = Don’t know (Skip to M10)

98 = Decline to say (Skip to M10)

1. *(If yes)* **What advice, suggestions, and/or referrals did they give you?**

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

1. **Is there anything else about HIV care you received since your delivery that you’d like to share with me or think I should know?**

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

### PART N: LIFE CHANGES AND SOCIAL SUPPORTS

**“Pregnancy can become a difficult time for any mother or birthing person. The next questions are about some common stresses or problems persons have told us happened to them during pregnancy.”**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| 1. **Do you feel that you were ever treated differently or unfairly in getting social services or healthcare because of …?** *(Read list and check all that apply.)* | 0  No | 1  Yes | 77  Don’t know | 98  Decline to say |
| Your race |  |  |  |  |
| Your age |  |  |  |  |
| Your culture |  |  |  |  |
| Your gender identity |  |  |  |  |
| Your citizenship |  |  |  |  |
| Your height or weight |  |  |  |  |
| Your physical appearance (how you looked or dressed) |  |  |  |  |
| The type of insurance you had |  |  |  |  |
| Your partner |  |  |  |  |
| Your HIV status |  |  |  |  |
| Your child’s HIV exposure status |  |  |  |  |
| Your sexual orientation |  |  |  |  |
| Disability status |  |  |  |  |
| Other |  |  |  |  |
| *specify*):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | | | |
| Did not experience different or unfair treatment |  |  |  |  |

**“Now I will ask you about things that could have caused stress during different times related to your pregnancy.”**

1. **Were there things that happened during your pregnancy or since delivery that caused additional stress, such as problems at work, someone close to you getting sick or you and your husband/partner arguing? Tell me about them.**

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

**“These next few questions are about support you received.”**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| 1. **During your pregnancy or since delivery, was there someone who…** *(Read and check all that apply)* | 0  No | 1  Yes | 77  Don’t know | 98  Decline to say |
| Could help take care of you if you were sick in bed? |  |  |  |  |
| Could run errands for you or watch your children if you needed help? |  |  |  |  |
| You could turn to if you needed to borrow some money? |  |  |  |  |
| You could confide in if you needed to talk to someone? |  |  |  |  |

1. **Was there ever a time during your pregnancy or since delivery that the support you really needed was not available?**

0 = No *(Skip to N6)*

1 = Yes

77 = Don’t know *(Skip to N6)*

98 = Decline to say *(Skip to N6)*

|  |
| --- |
| *IF “No”, “Don’t know”, “Decline to say”, SKIP TO N6* |

1. (If yes) **Please tell me a little more about what kind of support or help you felt you needed**:

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

**“Sometimes people experience violence. Talking about this can be painful and difficult. Because we want to improve our response to people’s health and safety, we have some questions about violence. We appreciate you responding to these sensitive questions.”**

|  | **Before this pregnancy** | **During this pregnancy** | **Since your delivery** |
| --- | --- | --- | --- |
| 1. **Has anyone threatened to hurt or kill you, prevent you from leaving or entering your house, or prevent you from seeing friends or making phone calls?** *(Read and one for each reference period)* | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say |
| 1. **Did anyone hit, slap, kick, punch, push or physically hurt you?**   *(Read and check one for each reference period.* | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say |
| 1. **Did anyone ever force you to have sex when you did not want to have sex?** *(Read and check all that apply)* | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say | 0 = No  1 = Yes  77 = Don’t know  98 = Decline to say |

|  |
| --- |
| *IF “No” to* ***ALL*** *questions in N6-N8, SKIP TO N10* |

1. **What kind of help did you receive?**

1= none

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

Instructions for the interviewer:

If violence disclosed, say: “At the end of the interview, I will talk with you more about how we can help you with this.”

1. **Since your delivery*,* how often have you felt depressed?**

1 = Never

2 = Rarely

3 = Sometimes

4 = Often

5 = Always or almost always

77 = Don’t know

98 = Decline to say

1. **Have you been referred to any health or human service for depression?**

0 = No

1 = Yes. Referral made, and services provided.

2 = Yes. Referral made, but services not provided.

77 = Don’t know

98 = Decline to say

1. **Since your delivery, has a health care provider diagnosed you as being depressed or having other mental health conditions, such as anxiety?**

0 = No *(Skip to N14)*

1 = Yes

77 = Don’t know (*Skip to N14)*

98 = Decline to say *(Skip to N14)*

|  |
| --- |
| *IF “No”, “Don’t know”, or “Decline to day”, SKIP TO N14* |

1. (If yes) **What did your health care provider tell you?**

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

1. **Were there any other events during your pregnancy or since delivery that caused additional stress or is there anything else about common stresses or support in general that you’d like to share with me?**

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

### PART O: CHILD’S HEALTH AND HIV CARE

|  |
| --- |
| *If fetus, infant or child death occurred in the hospital, SKIP TO PART P: Closing* |

**“I will now shift the interview to focus on [CHILD’S NAME] and the health care he/she received after leaving the hospital.”**

1. **After leaving the hospital, did [CHILD’S NAME] live with you at least some of the time?**

0 = No

1 = Yes *(Skip to O2)*

77 = Don’t know

98 = Decline to say

**O1b. Describe any significant challenges faced by the child, the family, the systems with which they interacted, or the response to experience with child protective services.**

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

|  |  |
| --- | --- |
| *IF “No”, “Don’t know” or “Decline to say”, SKIP TO PART P: Closing* |  |

1. (If yes)**Do you take care of most of [CHILD’S NAME] day-to-day needs?**

0 = No

1 = Yes *(Skip to O4)*

77 = Don’t know *(Skip to O4)*

98 = Decline to say *(Skip to O4)*

|  |
| --- |
| *IF “Yes” “Don’t know”, “Decline to say”, SKIP TO O4* |

1. (If no) **Who is responsible for taking care of [CHILD’S NAME] day-to-day needs?**

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

1. **Have you ever had a problem paying for any medical care for [CHILD’S NAME]?**

0 = No

1 = Yes

77 = Don’t know

98 = Decline to say

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| 1. **How did you pay for [CHILD’s Name] care?** *Check all that apply* | 0  No | 1  Yes | 77  Don’t know | 98  Decline to say |
| Private insurance |  |  |  |  |
| Medicaid |  |  |  |  |
| Medicare |  |  |  |  |
| SCHIP (CHIP/Children's Health Insurance Program) |  |  |  |  |
| Ryan White program |  |  |  |  |
| ADAP |  |  |  |  |
| CHAMPUS/Military insurance |  |  |  |  |
| Self-pay, but eligible for Medicaid |  |  |  |  |
| Self-pay |  |  |  |  |
| Local or hospital-based assistance |  |  |  |  |
| Other |  |  |  |  |
| Other (specify): |  |  |  |  |

1. **What barriers, if any, do you have when seeking routine well-baby care for CHILD’S NAME]** *(Keep open-ended and check all appropriate responses)*

|  |
| --- |
|  |

1 = No transportation or unreliable transportation

2 = No money for medical provider’s visits

3 = No insurance for [CHILD’S NAME]

4 = No childcare

5 = Did not know where to go

6 = No time/unable to get time off from work

7= Facility hours did not work with schedule

8 = Unable to get an appointment for [CHILD’S NAME]

9 = Wait time or wait list for an appointment was too long

10 = Staff doesn’t listen to her

11 = Language services not available

12 = Staff not liked or trusted

13 = Unable to get a medical provider or nurse to take [CHILD’S NAME] as a patient

14 = Doesn’t think it helps [CHILD’S NAME]

15 = Other

16 = **(***specify):* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

17 = No problems

77 = Don’t know

98 = Decline to say

**“I would like to ask you about illnesses or injuries that [CHILD’S NAME] developed after leaving the hospital?”**

1. **After leaving the hospital, how many times was [CHILD’S NAME] seen for any illness or injury by a medical provider?**

\_\_\_\_\_ times (*Enter zero if not seen by a medical provider for illness or injury)*

77 = Don’t know

98 = Decline to say

|  |
| --- |
| *IF “0” times, SKIP TO O9* |

1. ***If greater than zero, w*hy was [CHILD’S NAME] seen by a medical provider?**

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

1. **After leaving the hospital, how many times was [CHILD’S NAME] hospitalized overnight?**

0 = None *(Skip to O11)*

1 = 1 One time

2 = 2 Two times

3 = 3 Three times or more

77 = Don’t know

98 = Decline to say

|  |
| --- |
| *IF O9 IS “0/NONE”, SKIP TO O11* |

1. **Why was [CHILD’S NAME] hospitalized?** *(Ask reason for each time hospitalized).*

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

1. **Is there anything else about [CHILD’S NAME], their health or general care that you’d like to share with me or think I should know?**

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

**“Now I’m going to ask you some questions about [CHILD’s NAME]’s HIV care and medications.”**

1. **What has [CHILD’S NAME]’s medical provider said about [his/her] HIV status?**

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

1. **How long did [CHILD’S NAME] receive care for HIV exposure and HIV testing?**

0 = Did not receive care

1 = 4-6 weeks

2 = Less than 4 weeks

3 = More than 6 weeks

4 = Other *(specify*): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

77 = Don’t know

98 = Decline to say

1. **Was it difficult to attend medical appointments for both you and your baby after (child’s name) was born?**

0 = No

1 = Yes

2 = Mother or birthing person did not receive HIV care postpartum

77 = Don’t know

98 = Decline to say

1. **Can you tell me a little more? (Interviewer prompts: What made it easy or difficult?)**

|  |
| --- |
|  |
|  |

1. **What things, if any, kept [CHILD’S NAME] from getting HIV care or testing?** *(ask open-ended and check all that apply)*

|  |
| --- |
|  |
|  |

1 = No transportation or unreliable transportation

2 = No money for medical provider’s visits

3 = No insurance for [CHILD’S NAME]

4 = No childcare

5 = Did not know where to go

6 = No time/unable to get time off from work

7= Facility hours did not work with schedule

8 = Unable to get an appointment for [CHILD’S NAME]

9 = Wait time or wait list for an appointment was too long

10 = Staff doesn’t listen to her

11 = Language services not available

12 = Staff not liked or trusted

13 = Unable to get a medical provider or nurse to take [CHILD’S NAME] as a patient

14 = Doesn’t think it helps [CHILD’S NAME]

15 = Other

16 = **(***specify):* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

17 = No problems

77 = Don’t know

98 = Decline to say

| 1. **It is sometimes difficult to give a baby medication. What barriers, if any, have you had in giving [CHILD’S NAME] [his/her] medicine?** *(Check all that apply)* | 0  No | 1  Yes | 77  Don’t know | 98  Decline to say |
| --- | --- | --- | --- | --- |
| Problem getting medicines (e.g., couldn’t get to pharmacy, special order required) |  |  |  |  |
| Ran out of medicine |  |  |  |  |
| Unable to pay for the medicines/insurance issues (e.g., co-pay) |  |  |  |  |
| Misplaced or spilled the medicines |  |  |  |  |
| The baby spits it up |  |  |  |  |
| The baby gets side effects |  |  |  |  |
| Worried about what the HIV medicines might do to the baby |  |  |  |  |
| Lack of support from others in helping with giving the baby the medicines |  |  |  |  |
| Forgot to give the baby medicine |  |  |  |  |
| Baby’s medication is scheduled during work, sleep times, or other busy times |  |  |  |  |
| Travel or changes in schedule interfered with the baby’s medication schedule |  |  |  |  |
| Worried that someone will find out that the baby may have HIV |  |  |  |  |
| Other |  |  |  |  |
| (*specify): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_* | | | | |
| No problems |  |  |  |  |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| 1. **At any time, do you feel that [CHILD’S NAME] was ever treated differently or unfairly in getting any support services or seeing any providers?** *(Read and check all that apply)* | 0  No | 1  Yes | 77  Don’t know | 98  Decline to say |
| Race |  |  |  |  |
| Culture or ethnic background |  |  |  |  |
| Citizenship status |  |  |  |  |
| HIV exposure status |  |  |  |  |
| Mother or birthing person and partner’s marital status |  |  |  |  |
| Type of insurance |  |  |  |  |
| Ability to pay for services |  |  |  |  |
| Other |  |  |  |  |
| *(specify):* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | | | |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| 1. **Did [CHILD’S NAME] receive any health program assistance or social services?** *(Read and check all that apply)* | 0  No | 1  Yes | 77  Don’t know | 98  Decline to say |
| Public health nursing home visits or care |  |  |  |  |
| Respite/day care |  |  |  |  |
| County/state funded medical care, treatments, or equipment |  |  |  |  |
| Infant child health program |  |  |  |  |
| Well child check-up/Immunizations |  |  |  |  |
| Early Head Start |  |  |  |  |
| Ryan White |  |  |  |  |
| Social Security |  |  |  |  |
| WIC |  |  |  |  |
| Food assistance |  |  |  |  |
| CHIP/Medicaid health insurance |  |  |  |  |
| Case management/social worker assistance |  |  |  |  |
| Developmental or disability assistance |  |  |  |  |
| Early intervention evaluation |  |  |  |  |
| Other |  |  |  |  |
| *(specify):* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | | | |

**CHECK BOX BELOW IF CHILD HAS AN HIV NEGATIVE STATUS AND SKIP TO P24**

1. **CHILD HAS HIV NEGATIVE STATUS/FINAL STATUS PENDING**
2. **Is [CHILD’S NAME] currently prescribed HIV medications?**

0 = No

1 = Yes

77 = Don’t know

98 = Decline to say

1. **Did you receive counseling, connect with a peer, or join a support group for parents who have a child with HIV?**

0 = No *(Skip to O24)*

1 = Yes

77 = Don’t know *(Skip to O24)*

98 = Decline to say *(Skip to O24)*

|  |
| --- |
| *IF “No”, “Don’t know”, “Decline to say”, SKIP TO O24* |

1. (If yes) **Please tell me about your experience.**

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

1. **Is there anything else about [CHILD’S NAME] HIV testing and care and/or general medical care that you’d like to share with me or think I should know?**

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

### PART P: CLOSING

**“I have asked all of these questions so that I can understand more about you and your experiences before, during and since your recent pregnancy. We are almost finished with the interview. I only have a few more questions for you. Your ideas are very important to us and may be helpful to make improvements.”**

1. **Is there anything else you’d like to tell me about your experiences since your pregnancy that you feel is important for me to know or that you want to share?**

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

1. **What in your pregnancy experience did you find to be really helpful or supportive for you and/or [CHILD’S NAME]?**

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

1. **Thinking back on your entire pregnancy experience, was there anything about the care you or [CHILD’S NAME] received that you think was not helpful?**

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

1. **Based on your experiences, what do you think can be done to better help persons with HIV and their children *(prompts: for example, anything related to the medical care received or how you were treated)?***

|  |
| --- |
|  |
|  |

77 = Don’t know

98 = Decline to say

**“This is the end of the interview. I have no further questions for you. Thank you very much for sharing your opinions and experiences.”**

Instructions to the interviewer: Provide appropriate informational materials, resources, and referrals. Please use space below to document any additional information, including pertinent details elicited by the interview but not recorded elsewhere, description of surroundings during the interview, etc.

1. **Comments:**

|  |
| --- |
|  |
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|  |
|  |