

Data Collection Forms Questions

5/12/2020

GENERAL QUESTIONS

1. What are HRSA's expectations and timeline for implementation?

Implementation Activities	Dates
Release of Forms	March 2, 2020
Training on Forms	April 2020
Practice Using Forms	April – May 2020
Begin using Data Collection Forms	May 15, 2020
Virtual Grantee Meeting – CAREWare Database* Demo & Data Forms TA	June 2020
Training on CAREWare Database	June/July 2020
Begin entering data into CAREWare Database (should include data collected from May 15th onward)	August 1, 2020
Release of HSMED2	October 2020
Training on HSMED2	October 2020
Data reporting via HSMED2	October 15, 2020

***CAREWare is not mandatory.** CAREWare is a *free* option for ALL grantees, which will be aligned to the new Data Collection Forms and will have case management capabilities.

2. Will Data Collection Forms be uploaded similar to how the Screening Tools were?

Yes. The Data Collection Forms can be downloaded at https://www.healthystartepic.org/healthy-start-implementation/data_collection_forms/

3. Which parts of the instructional text and public burden statements must be in [the software]?

For real-time interviewing/data entry: It is recommended that the entire form, including instructions and public burden statement, should be included in the software that is used. This is for the interviewer's benefit and can be referred to in the event that a client has a question that could be answered with this information.

For data entry only: The script does not need to be in the software. It may be useful to include some of the instructional text for data entry purposes.

4. When will the Spanish forms be released?

The Spanish forms will be released prior to June 1, 2020.

5. Is there a flowchart created for all Healthy Start programs to use? I have created one for our program to use and I can share.

We have not yet created a flowchart for all programs to use, but would be happy to consider and/or share those prepared by grantees. The TA Center may be able to prepare a flowchart, as well.

6. Interesting that Zip Code is no longer being collected. Are we not confined to serving our qualifying zip codes?

Zip code is considered Personally Identifiable Information (PII), which is not sent to HRSA. Grantees must serve participants who reside in the project service area outlined in their grant application.

PARTICIPANT TYPES DEFINED

Primary Participant (PP) – A woman who is enrolled in preconception, prenatal, postpartum, or parenting/interconception services; an enrolled father/male partner; or other adult (if applicable) who has primary responsibility/custody for an enrolled child.

Forms: The PP completes all applicable forms.

Enrolled Child (EC) – An infant or child up to 18 months. Infant is defined as 0-11 months of age. Child is defined as 12-17 months of age.

Forms: Only a Primary Participant may complete the Parent/Child Form.

Accompanying Adult (AA) – The Primary Participant’s spouse or partner, and/or the enrolled child’s co-parent. The AA is not enrolled in the program himself/herself.

Forms: The AA completes the Background Form only, but not the final two sections on “Pregnancy and Childbirth History” and “Previous Births.” The AA does not complete the Parent/Child Form or the Prenatal Form.

ENROLLMENT QUESTIONS

Preconception Women (PW)

- 1. Can we enroll women in the preconception stage? [The Prenatal Form states (pg. 1): “The mandatory Prenatal Form is to be completed...or as soon as it is known that an enrolled woman is pregnant.”]**

Yes. The Notice of Funding Opportunity (NOFO) states that grantees must serve per calendar year “300 infants/children up to 18 months and preconception/interconception women.”

- 2. Preconception women: What services would we provide? How often do they need to be seen?**

Some grantees have chosen to include preconception women in their recruitment strategies and planned services. Program participants, including preconception women, have direct contact with HS staff or subcontractors and receive HS case management/care coordination on an ongoing systematic basis to improve perinatal health and infant health. Sites should refer to their applications and work with their Project Officers regarding their planned activities with preconception women.

Child Enrollment

- 1. Can a site restrict the infant/child enrollment age for entry into the program? For example, can a program cut off enrollment of children at 12 months? Does it make sense to enroll a 17-month-old?**

The program site may not create a separate enrollment age cut-off for entry into the program. The NOFO states that the program is for children up to 18 months of age. In special situations, and if resources are available, the Project Officer may approve serving select children beyond the age of 18 months. (However, children over 18 months of age are not counted in the participant requirements.)

Accompanying Adult

- 1. Do Accompanying Adults count as enrollees?**

No, Accompanying Adults are not enrollees of the HS program. Enrollees are individuals having direct contact with the HS staff or subcontractors, and receiving case management and care coordination services on an ongoing systematic basis. Enrollees also complete consent forms to participate in the program.

BACKGROUND FORM

BACKGROUND FORM: INSTRUCTIONS

- 1. Please clarify, when is the background information form to be administered?**

The Background Information form is to be administered at intake, and then updated at phase changes, at annual visits, and on program exit, if possible. The entire Background Information form is updated (meaning a new form is completed) with the PP when: (a) an enrolled woman becomes pregnant; (b) an enrolled woman's pregnancy ends; (c) an enrolled infant turns 6 months old, and (d) other PP update, such as a major life event (e.g., divorce) or a significant change in health status. The form may be updated if a PP continues enrollment after the enrolled child exits the program. In addition, when possible, it is updated with the PP and/or AA on program exit.

- 2. What is the time frame to complete the forms (1st visit, within 3 visits)?**

The Background Information form should be completed within 30 days of the visit or beginning the form.

- 3. If the form was started, but completed in a later date, how should the form be dated?**

Forms should be completed within 30 days of the visit or beginning the form. The date of completion should be indicated.

- 4. Instructions, Page 1: "Upon phase change, only the primary participant's form is updated." Is the "Primary Participant's form" referring to the Background information form?**

Yes, this instruction refers to the Primary Participant's Background Information form. When "updating" the Background Form, the entire Background Form is completed; previous versions are not overwritten or erased.

- 5. Instructions, Page 1: "Upon Phase Change, Only the Primary Participant's Form is updated." Does "phase change" include when an infant turns 6 months of age or when an older child exits the program but the Primary Participant and Accompanying Adult continue to receive services?**

Yes, the Primary Participant's Background Information form is updated when an infant turns 6 months old, or when an older child exits the program, but the Primary Participant continues to receive services.

- 6. a. Do we complete this form for the Accompanying Adult, if that person is a male?
b. Does a full Background Info form need to be completed for an Accompanying Adult?**

Yes, both male and female Accompanying Adults complete the Background Information form. However, Accompanying Adults do not complete the final two sections on "Pregnancy and Childbirth History" and "Previous Births."

BACKGROUND FORM: GENERAL INFORMATION (Pages 1-4)

1. Question 1 – Participant Type:

Accompanying Adult response options are "Yes" and "None" – is the response to this question supposed to indicate if an AA exists (and therefore supposed to be answered by anyone completing the form), or if the person completing the form is an AA (only to be answered by an AA)?

The purpose of this question is to (a) indicate whether the participant completing the form is a Primary Participant (PP) or an Accompanying Adult (AA), and (b) determine whether the PP has an AA whose data needs to be linked to his/hers.

When the PP completes the Background Information form, she/he:

- Will not check the circle by "Accompanying Adult"
- Will check "None" or "Yes" under "Accompanying Adult"

When the AA completes the Background Information form, she/he:

- Will check the circle by "Accompanying Adult"
- Will not check "None" or "Yes" under "Accompanying Adult"

2. Question 1 – Participant Type:

If Primary Participant did not initially have an Accompanying Adult, but acquires one in later visits, how do we update the PP's form? Do we simply erase the check mark from "None" or would we also have to put a check mark on "Yes"?

In an update, the original form is essentially administered again. Information on the original form, or other previous forms, is not erased or overwritten. If a Primary Participant has no Accompanying Adult at intake but has one at an update, then "none" would remain checked in the original form, and "yes" would be checked in the update.

3. Questions 2 & 3 – Unique ID#:

What are the rules for creating the Unique IDs (numbers, characters, length)?

Each Unique ID# (UID) has 3 parts:

- a) Grantee OrgID, a 3-digit numeric code that indicates the program site (provided by HRSA)

- b) **Participant Code**, a two-letter indicating whether the data belongs to a primary participant (PP), accompanying adult (AA), or enrolled child (EC)
- c) **Participant Unique Number**, a unique ID assigned by the grantee site that should be at least 4 digits/letters or longer. This portion of the Unique ID# is determined by the grantee organization.

UID = OrgID (3 digits) + Participant Code (2 letters) + Participant Unique Number (4 or more characters)

For example, Grantee A (OrgID=123) is completing forms for a Primary Participant (ID=56789). The UID for this participant would be Grantee Org ID + Participant Code + Participant Unique Number, or 123PP56789. Grantee B (OrgID=135) is completing forms for an Enrolled Child (ID=967A2E). This participant's UID would be 135EC967A2E.

Each participant's unique ID stays with them even after she/he has exited the program. Participants may decide at a later date to re-enter the program, and we would want them to have the same UIDs so they can be tracked across time.

4. Questions 2 & 3 – Unique ID#:

If a client discharges then re-enrolls in the program is the same Unique ID used?

Yes, if a client is discharged and then later re-enrolls, the same Unique ID is used.

5. Question 4 – This participant has at least one enrolled child attached to her/him:

Under what circumstances should we mark "Formerly but no longer"?

The following scenarios are examples of when a program may select that option.

- a) The parent/guardian no longer wants to continue services for the child, but wishes to continue parenting/interconception services
- b) Child turns 18 months or older (no longer eligible), but the parent continues with interconception services
- c) Child is deceased
- d) Participant no longer has custody and/or the child is not receiving Healthy Start services
- e) Child participant is not living in the project service area

6. Question 5 – Dates of enrollment in Healthy Start:

What date is this asking for? The first date the client enrolled in Healthy Start? For example, some clients enrolled into Healthy Start in 2016 and graduated in 2018. If they become pregnant again in January 2020 and return to Healthy Start, do I write 2016 enrollment date or January 2020 date?

Use the current enrollment date (e.g., Jan 2020 in this example) for clients who have been enrolled previously and are returning to the program. The current enrollment date is the starting point for the current services.

7. Question 6 – What phase of the reproductive cycle was the Primary Participant in when he/she first enrolled in HS?

For Preconception Women, do we complete any other forms in addition to the Background Info Form?

No. Preconception women complete only the Background Information form. If a preconception woman becomes pregnant, that would count as a phase change and she would both update the Background Information form and complete the Prenatal Form.

8. Question 6 – What phase of the reproductive cycle was the Primary Participant in when he/she first enrolled in HS?

Assume that if a woman is pregnant, is she identified as pregnant even if she has children or a pregnancy loss less than 6 months ago?

Yes, a woman is identified as pregnant if she is pregnant, regardless of other circumstances that may have occurred. A pregnant woman with a child enrolled in HS will also complete the Parent/Child Form for that child.

9. Question 6 – What phase of the reproductive cycle was the Primary Participant in when he/she first enrolled in HS?

What options are available for mother primary participants vs. father primary participants?

A mother primary participant may enroll in the following categories: prenatal, postpartum, or parenting/interconception. A father primary participant may enroll in the parenting/interconception phase.

10. Question 6 – What phase of the reproductive cycle was the Primary Participant in when he/she first enrolled in HS?

Can we select multiple categories (e.g., a mom has an enrolled child and is pregnant)?

Yes, please check all applicable categories for the Primary Participant.

11. Question 6 – What phase of the reproductive cycle was the Primary Participant in when he/she first enrolled in HS?

Under Parenting/IC, there is an option for “has children, but they are not enrolled or are not eligible for HS services.” Does this mean we can enroll:

- a. A woman whose youngest child is over 18 months old - even if that child is, for example, 3 years old, or is there an age limit?** Yes, an interconception (IC) woman of reproductive age (15-44 years old) can be enrolled.
- b. Women who are not able to conceive?** The NOFO states that a woman must be of reproductive age; it does not specify reproductive ability. The program should determine how they wish to handle such cases and work with their Project Officer regarding specific questions.
- c. If we enroll the above women, do we complete any other tool besides the Background?** No, only the Background Information Form should be completed.

12. Question 7 – Initial Completion of this Form (PP or AA):

What is key date for the form – Initial completed date or add Administration Date?

The “date form completed” is the initial completed date. The section on updating the form has spaces to write the dates for each update.

13. Question 8 – When to update the form with PP:

If a PP was prenatal and enrolled in November, would the Background Form need to be updated in January or only when she delivers?

The Background Information form would need to be updated when she delivers.

14. Question 8 – When to update the form with PP

Question 9 – Updating the form when PP or AA exit the program:

Could you provide more in-depth information on your expectations for updates and when they need to occur?

The entire Background Information form is updated (meaning a new form is completed) with the PP when: (a) an enrolled woman becomes pregnant; (b) an enrolled woman's pregnancy ends; (c) an enrolled infant turns 6 months old, and (d) other PP update, such as a major life event or significant change in health status. The form may be updated if a PP continues enrollment after the enrolled child exits the program. In addition, when possible, it is updated with the PP and/or AA on program exit.

15. Question 8 – When to update the form with PP:

What part of the Background Form is being updated after birth?

The entire Background Form is updated.

16. Question 8 – When to update the form with PP:

Define phase change for custodial mother primary participants vs. phase change for custodial father primary participants. For ex. If a custodial father primary participant has a child in the program and his partner, who may or may not be an accompanying adult, becomes pregnant, is that a phase change for a custodial father primary participant?

A custodial father would undergo a phase change only when the enrolled child turns 6 months old and at program exit, if possible. His partner's pregnancy would not count as a phase change for him because she is not enrolled in HS, so her pregnancy is not tracked by HS.

17. Question 8 – When to update the form with PP: "Other update (...annual reporting occurs with no phase change on primary participant's part...)"

Does the background of every PP and AA need to be updated at the beginning of the year?

No. But if a client remains active, and a year has gone by without an update (e.g., no phase change has occurred for a year), then an update should occur at the next client interaction.

18. Question 8 – When to update the form with PP:

How do we determine what to update for each of these scenarios (entering a prenatal phase, ending a prenatal phase, etc.)? Would we ask all questions all over again, essentially doing a new Background Form? If so, are we erasing and overwriting or are we doing it on a brand-new Background Form that includes relevant info from previous versions? How is this handled for someone who becomes pregnant twice or gives birth twice in the same calendar year?

The entire Background Information form is updated (meaning a new form is completed) with the PP when: (a) an enrolled woman becomes pregnant; (b) an enrolled woman's pregnancy ends; (c) an enrolled infant turns 6 months old, and (d) other PP update, such as a major life event or significant change

in health status. The form may be updated if a PP continues enrollment after the enrolled child exits the program. In addition, when possible, it is updated with the PP and/or AA on program exit.

19. Question 8 – When to update the form with PP:

How should we interpret the way to update the Background Form? Do we cross out or overwrite the information on the Background Form to be replaced with new info. or do we create a new Background Form that contains the relevant info. from the previous version(s)? e.g. questions 5-7 under General information regarding initial enrollment. If we are overwriting info. and using a paper form, for example, would that entail using pencil so we can keep one Background Form to move with the participant through their time with us and allow us to easily erase info. and replace it with new info?

The entire Background Information form is updated (meaning a new form is completed) with the PP when: (a) an enrolled woman becomes pregnant; (b) an enrolled woman's pregnancy ends; (c) an enrolled infant turns 6 months old, and (d) other PP update, such as a major life event or significant change in health status. The form may be updated if a PP continues enrollment after the enrolled child exits the program. In addition, when possible, it is updated with the PP and/or AA on program exit.

During an update, the caseworker should go over each of the questions, remind the participant of how he/she answered them originally, and ask if the answers are the same or should be changed. Information on the original form is not erased or overwritten. The new form has a place to indicate whether it is the initial form or an update, so changes can be tracked across time for an individual.

20. Question 9 – Updating the form when PP or AA exit the program:

Exit screening: a fair number of clients are "lost to follow-up" so we may not be able to screen all participants on exit.

It is understood that a certain percentage of clients will leave without the opportunity to provide an exit interview. This is considered attrition. Clients who have "completed" their intended services and have a planned exit from the program should have an exit interview, which would include updating the Background Information form. For clients who abruptly announce they are leaving, please do an exit interview, if possible.

BACKGROUND FORM: PARTICIPANT GENERAL INFORMATION

1. Question 1 – What is your sex?

Question 1a – [Staff: Indicate here if participant expresses discomfort with or reluctance to use the male/female binary classification.]

For the male/female binary question, could we add as an option "not applicable or not relevant"? I don't think this question is culturally sensitive or that other communities care about this.

No; unfortunately, the forms may not be changed because they have been approved by the Office of Management and Budget as they are written, and implementing changes would require a new, lengthy review. To address this limitation, there are two questions related to sex/gender. The first asks clients to identify their sex using standard categories for this question. If a client expresses discomfort with the

binary male/female categories, check “declined to answer.” The subsequent question (#1a) provides an opportunity to capture the client’s preference for a non-binary categorization.

- 2. Question 2 – What is the highest grade or level of school that you have completed?
If they completed their native country's version of high school, which may or may not have a 12th grade, can we still opt for the "High school diploma (Completed 12th grade)" option?**

Yes, if a client completed the equivalent of a high school diploma in his/her home country, then you would put a checkmark next to “high school diploma” here.

- 3. Question 4 – What is your race?
There is no "Other" option. We service people that do not fall under the current options given.**

If the client does not identify with any of the races provided, check “don’t know” or “declined to answer.” The client may indicate his/her specific race preference in Question 5, “Other.”

- 4. Questions 4 – What is your race?
Question 5 – Which one racial classification below do you identify with the most?
Which do we use for reporting: #4 which asks for all applicable races, or #5 which asks for the race that the client most identifies with?**

Ask both Questions 4 and 5. Question 4 uses a standard format for capturing race, where the client selects all that apply (or declines to answer). This allows comparison to national population estimates of race within the U.S. Question 5 asks for the client to select a single racial identity (including “multiracial” or “other”); this allows a single race variable to be associated with each participant, which facilitates certain types of counts and analyses.

BACKGROUND FORM: PARTICIPANT HEALTH CARE

- 1. Question 7 – Where do you USUALLY go (for care when sick) first?
Does "some other place" mean urgent care only? Or, how's this option different than "other"?**

Any place that does not fall into one of the given categories would be designated as “some other place,” and this includes urgent care.

- 2. Question 7 – Where do you USUALLY go (for care when sick) first?
If the participant does have a primary doctor and doesn't usually go there first, but eventually does go there for follow up, do we still pick where they go first?**

Yes. Please indicate where they usually go first, even if it is not their primary doctor’s office.

- 3. Question 9 – What kind of health insurance do you have now?
Can we add "not eligible" as a response?**

If a person is not eligible for insurance, then “I do not have health insurance now” should be checked. [Unfortunately, the forms may not be changed because they have been approved by the Office of Management and Budget as they are written, and implementing changes would require a new, lengthy review.]

4. Question 9 – What kind of health insurance do you have now?

If mom is young enough to be eligible for CHIP, and she tells us that she only knows she has Medicaid, what is the best option? What about her children, if she tells us they have Medicaid, should we assume and mark it as CHIP on their relevant forms?

The caseworker should not impose his/her response in lieu of the client's response. If the caseworker is fairly certain that the client or her child has CHIP, the caseworker may mention the possibility to the client to see whether it makes sense to report CHIP on the form.

5. Question 10 – During the past 12 months, did you see (someone) for preventive care? Is a postpartum visit considered "preventive medical care"?

No; a postpartum visit is not considered preventive medical care.

6. Question 10 – During the past 12 months, did you see (someone) for preventive care? Does it include OB/GYN care/check-up that is not prenatal care?

If a woman sees an OB/GYN as her regular primary care person or for standard gynecological check-ups, then it would be considered preventive.

BACKGROUND FORM: PERSONAL WELL-BEING

1. Question 11 – Total Household Income during the past 12 months:

There is no option for "don't know" or "declined to answer." Just leave blank if one of those apply?

Yes; leave it blank.

2. Question 13 – Of all the people who depended on this income during the past 12 months, how may are...?

Would a PP under the age of 18 [years] be "counted" as a child? If an "underage" PP lives with her parents, would you obtain the parents income information? If the underage PP is not living with family, could it be a child with no "Adult" indicated?

The answer may depend on whether the PP is dependent on her parents. If 17 or younger AND dependent on parents, then PP is counted as a child dependent on the parents' incomes. If 17 or younger AND independent/living elsewhere, count the PP as a child living on the appropriately-determined income.

3. Question 14 – Do you have any children less than 18 months old who are enrolled or you would like to enroll in Healthy Start?

Do we answer this for both the Primary Participant AND the Accompanying Adult (thus duplicating data) or just answer for Primary Participant?

Question 14 is provided in order to: (a) determine whether a woman enrolling has any children eligible for services, as well, (b) remind the caseworker about the forms that need to be completed when that is the case, and (c) provide an additional data point that serves as a reminder that this adult (whether primary participant or accompanying adult) will have a child linked to him/her in the database.

4. Question 17 – Additional Depression Screening:

If the client had a positive screen but was evaluated by a professional and was found to not need or declined services following evaluation would you check "Client is already receiving services"?

No, in this case the second option should be checked, "Participant's total score of 3 or more indicates that additional screening and referral is needed and referral was provided."

5. Question 17 – Additional Depression Screening:

Can the option of "Participant was screened, but did not score 10 or more on the Edinburgh" be added as an option for #17 on the Background Information Form.

No; unfortunately, the forms may not be changed because they have been approved by the Office of Management and Budget as they are written, and implementing changes would require a new, lengthy review. The site can screen using the EPDS and record the score in their system, but it should not be reported to HRSA.

6. Question 18 – Substance Use:

Marijuana is a separate option without any designation of it being prescribed or not (for those states that have legalized medical marijuana). However, the instructions indicate that only responses indicating non-medical use will be recorded? How should it be recorded when someone reports they use medical marijuana?

There is no way to indicate this detail on the current form. The program should indicate frequency of marijuana use on this form, even if prescribed, as it relates to topics such as in utero exposure.

7. Screening follow-up:

Does HRSA plan to define a "positive substance or IPV screen"?

HRSA will provide a companion guide to address these types of questions that lack scoring guidance and recommended follow-up. Data will not be collected from these additional questions, but they will be provided for the benefit of the interviewer and client.

BACKGROUND FORM: REPRODUCTIVE LIFE PLAN (RLP)

1. Reproductive Life Plan:

Where, how, and at which moment are we addressing RLP?

Questions 21 through 26 of the Background Information form pertain to creation of the Reproductive Life Plan. These questions are asked when first completing or updating the Background Information Form.

2. Question 21 – Do you want any (more) children?

Can "unable to get pregnant" be chosen by a custodial father primary participant who wants more children but whose partner, who may or may not be an Accompanying Adult, is unable to get pregnant?

This question is answered from the perspective of the person completing the form. Please use whatever response the participant provides. For example, the father may wish to respond, "yes" or "unable to get pregnant." Either response is fine.

3. Question 23 – How long do you plan to wait until you become pregnant (again)?

How are we posing this question for custodial father primary participants?

Add the phrase “or your partner” when you ask the question, so that it is appropriate for males (or other partner types) and read, “How long do you plan to wait until you (or your partner) become pregnant again?”

4. Questions 24 and 25:

Questions 24 and 25 start with "All participants...", but 21-23 do not. Are we not asking these questions of custodial father primary participants?

Question 21 (“Do you want more children?”) establishes a skip pattern. Questions 22 and 23 are answered only when respondents indicate that they do want more children. The “All participants” at the beginning of questions 24 and 25 clarify that the earlier skip pattern has ended and that all clients should answer these questions, regardless of whether they want (more) children or not. *[Please note that there is a mistake: Q24 should not start with “all participants,” as those who are unable to get pregnant are supposed to skip this question about birth control.]*

5. Question 24 – Birth Control Method:

Do Accompanying Adults need to answer this question? And, do they answer based on the Primary Participant’s method of birth control?

All Accompanying Adults should answer this question based on their own practices or they may decline to answer. [If the Accompanying Adult is not a spouse/partner to the Primary Participant, but a grandmother (or other similar figure not directly involved in the Primary Participant’s RLP), she/he may wish to decline to answer.]

6. Question 26 – Has this participant responded to the questions to create a satisfactory RLP?

What questions fulfill the "satisfactory RLP" for mother primary participants vs. father primary participants? What about accompanying adults (female and male)?

The same criteria are used for all participants. That is, if she/he does not want (more) children, then she/he has identified a method of birth control to use to prevent pregnancy (q 24); or, if he/she does want (more) children, then he/she has thought about how many (q 22), their spacing (q 23), and how to prevent pregnancy until ready (q 24).

7. Question 26 – Has this participant responded to the questions to create a satisfactory RLP?

If the client has answered all questions but they are still vulnerable to an unplanned pregnancy, is that considered a “satisfactory RLP”?

No, if they are still vulnerable to unplanned pregnancy, then they have not yet created a satisfactory RLP, even if they answered all questions.

BACKGROUND FORM: PREGNANCY AND CHILDBIRTH HISTORY

1. Question 28: Have you ever had any of the following?

Does the "Number" refer to the number pregnancy (i.e. first, second, etc.) or how many times the participant experienced that outcome (i.e., 2 live births, 3 miscarriages, etc.)?

It refers to how many times the participant has experienced that outcome.

PRENATAL FORM

PRENATAL FORM: INSTRUCTIONS

1. On the Prenatal Form, what does the "post pregnancy follow up" refer to, another form?

The post-pregnancy follow-up is a section at the end of the Prenatal Form where the caseworker records the outcome of the pregnancy. It consists of 5 questions regarding the outcome of the pregnancy represented by that Prenatal Form. These 5 questions are a staff record.

PRENATAL FORM: GENERAL INFORMATION

1. Question 4 – Date of Initial Completion, Question 5 – Date Updated:

How should the form be dated since there are two sections and form is subject to update?

The date of initial form completion contains the date when the Prenatal Form is completed. The date for any updates, including the Post-pregnancy Record, is recorded in question 5 of the cover sheet.

PRENATAL FORM: PREGNANCY AND HEALTH

1. Question 1 – Baby's due date

Does this only relate to the due date at intake? Or, if the due date changes, should it be updated?

This is the due date noted at intake or when the Prenatal Form is completed. If the participant shares that her due date has been updated, the Prenatal Form is not updated; however, staff should use the revised due date when completing related questions on the Parent/Child Form. For example, the revised due date should be used in determining the number of weeks pregnant the mother was at birth (q5) and whether the child was preterm at birth (q6).

2. Question 2 – How many weeks pregnant are you?

Question 3 – What trimester is the client currently in?

Question 4 – When did the participant enroll in Healthy Start? (in relation to pregnancy trimester)

Questions 2-4 suggest that the number of weeks of pregnancy may not be known at intake into Healthy Start. The assumption is that questions 2 and 3 are answered based on when that information becomes available and question 4 would be a "look back" to weeks of pregnancy at the time of intake. If a woman knows her due date at HS intake, questions 2-4 would all be answered from the same time perspective. Is this accurate?

No, Question 2 does have a space for the client to answer how many weeks pregnant she is. Based on this response, Question 3 determines her current pregnancy trimester. Question 4 asks for the trimester she was in at the time of HS enrollment.

3. Question 4 – [Staff, when did the participant enroll in Healthy Start?]

It's confusing as this whole section is for enrolled women who are pregnant, but question 4 is still asking about when the mom enrolled.

This question asks staff to determine when the client enrolled in HS in relation to her current pregnancy trimester. The staff would need to refer to the client's date of enrollment to determine the client's associated trimester. For example, if the date of enrollment pre-dated the pregnancy, then the staff would check "Prior to this pregnancy." If the date of enrollment occurred when the woman was 12 weeks pregnant, the staff should check "First trimester." *The brackets, "[Staff...]", around the question indicate that this is a question to the staff only, and that this question is not read aloud to the client.*

4. Question 5 – How many months pregnant were you when you had your first visit for prenatal care?

Question 5a – [If has not yet had her first visit] Do you have an appointment scheduled?

Does a first prenatal appointment occur when the pregnant woman first meets with a medical provider? Some clinics in our area may have someone not eligible for "independent practice" take a history and/or schedule lab work prior to the woman actually being able to see the provider.

A prenatal visit is one in which a physician or other health care professional examines or counsels the pregnant woman for her pregnancy. It does not include visits for laboratory and other testing in which a physician or health care professional did not examine or counsel the pregnant woman. And, it does not include classes, such as childbirth classes, where the physician or health care professional did not provide individual care to the pregnant woman.

5. Question 5 – How many months pregnant were you when you had your first visit for prenatal care?

Is the first prenatal visit considering any prenatal visit or a prenatal visit at our organization?

The first prenatal visit refers to any prenatal visit; it did not have to take place at the HS organization.

6. Question 5 – How many months pregnant were you when you had your first visit for prenatal care?

Question 6 – Select the corresponding trimester for when the woman had her first prenatal care visit:

A question regarding questions #5 & 6 of the Prenatal Form, the data collection tools ask for months at first prenatal visit and when specifying trimester - weeks are the example/measure given. Please provide guidance on how to work with two forms of measurement. Are months integer only and if so please provide guidance on rounding?

The 1st trimester would be 1-3 months or 0-13 weeks, 2nd trimester would be 4-6 months or 14-27 weeks, and 3rd trimester would be 7-9 months or 28-40+ weeks.

7. Question 7 – Health Conditions:

Does latent or inactive tuberculosis qualify as a chronic condition?

Yes, it may be important to note should the patient need education, referral, or treatment.

8. Question 7 – Health Conditions:

Would behavioral health issues allow participants to be referred?

Yes.

- 9. Question 8 – Thinking about your child who was born just before the one you’re now pregnant with, how old was he/she when you learned about this pregnancy?
Does question 8 only apply to phase change (i.e., already having a child in the program and now pregnant again)?**

The purpose of Question 8 is to determine an interconception interval (pregnancy spacing).

- 10. Question 8 – Thinking about your child who was born just before the one you’re now pregnant with, how old was he/she when you learned about this pregnancy?
A question regarding question #8 of the Prenatal Form, is this question only for women who have live children?**

The question is about interconception interval, so it should refer to any pregnancy regardless of outcome.

- 11. Question 8 – Thinking about your child who was born just before the one you’re now pregnant with, how old was he/she when you learned about this pregnancy?
#8 how old was prior child when you learned about this pregnancy: the wording of our Benchmark is: women who reconceive within 18 months of previous birth. #8 does not answer that question since “learning of the pregnancy” is not when they conceived; why do we have this question?**

This question provides a ballpark estimate for the pregnancy interval.

- 12. Question 10 – Would you describe your partner or the father of this baby as [select only one] A question regarding question #10 of the Prenatal Form, how would you advise sites when they have a partner who is supportive but unable to be involved (e.g., someone incarcerated)? Or, how would you advise sites when they have a partner who passed recently and was supportive of the pregnancy?**

The client should select whichever option best describes the relationship. For example, if the father is incarcerated, but is supportive and as involved as possible (e.g., asks about the pregnancy), the mother may wish to select the first option “involved and supportive.” The same applies in situations where the partner may have passed.

- 13. Question 11 – How many cigarettes are you smoking now on an average day?
A question regarding question #11 of the Prenatal Form, the question asks about current smoking habits but the response option if they don't smoke is "I didn't smoke then" Please clarify if this question is asking about current smoking habits or previous habits. If previous, please provide a time frame or change response option to I don't smoke.**

This question is about current smoking habits; the option, “I didn’t smoke then” was a mistake. When reading the responses aloud to the client, staff should replace “I didn’t smoke then” with “I don’t smoke.” Unfortunately, the forms may not be changed because they have been approved by the Office of Management and Budget as they are written, and implementing changes would require a new, lengthy review.

PRENATAL FORM: POST-PREGNANCY FOLLOW-UP

- 1. What further guidance can be provided regarding a timeframe to "confirm the details" on the Prenatal Form in the post-pregnancy follow-up section (i.e. within 30 days), especially considering in #3 of that section, it needs to be noted if a neonatal death (within 27 days) occurred.**

The program should determine the best timeframe to confirm the details. For a high-risk client, the program may wish to check in as early as possible, whereas the program may wait 4-6 weeks for an appointment with a low-risk client.

- 2. Post-Pregnancy Follow-Up: The assumption is that the Prenatal Form needs to be updated at discharge if the participant leaves the program prior to delivery. Is this correct?**

Yes. The Post-Pregnancy follow-up should be completed with all women who receive prenatal care services while enrolled in HS, regardless of whether they are discharged or continue with HS following the end of the pregnancy. It is a staff record of the outcome of the pregnancy. It is completed as a staff record rather than as part of an interview because of the sensitivity of the questions should the pregnancy not end with a healthy baby. It is placed at the end of the Prenatal Form so that the pregnancy outcome does not become separated from the Prenatal Form it represents.

- 3. Post-Pregnancy Follow-Up: Questions 1-4 last bullets ask "Describe methods used to track... Question 5 asks about Source(s) of information. Are methods to track and sources the same thing? And does question 5 relate to questions 1-4?"**

Yes, they are asking for the same type of information, and question 5 would cover questions 1-4. If staff are unable to track the outcome, then the "describe methods used" portions of questions 1-4 would allow the grantee to keep track of steps they have taken to find the information.

PARENT/CHILD FORM

PARENT/CHILD FORM: INSTRUCTIONS

- 1. Do we complete one form for each child if the mother has more than one child enrolled in HS, such as one child and one newborn?**

Yes, complete one form for each child enrolled in Healthy Start, including children who are multiples.

- 2. How often and what time frame should the form be completed in?**

The Parent/Child Form should be completed at birth or when a newborn, infant, or child is newly enrolled in the program. The form is updated at 6 months of age (which represents a phase change from postpartum to interconception/parenting), and at 18 months of age (planned program exit). If the infant/child leaves the program before 18 months of age, update the form on exit from the program, if possible. The form should be completed within 30 days of the participant's enrollment and/or any phase change, when possible.

- 3. What does updating this form entail?**

To update the Parent/Child Form, the caseworker will complete a new Parent/Child Form. The caseworker goes over the client's previous form with the original or most recently updated answers to each

of the questions and asks, “is this still the case or has this changed?” The answers on the original/previous form(s) are not erased or overwritten. There is a place on the form to indicate whether it is an initial completion or an update.

- 4. For the 6 month update, are we exclusively asking questions specifically for the 6 month mark (like question 18 and then also updating question 17)? Or will we ask all questions, essentially creating a new form? If the latter, will we erase and overwrite info. from the past form? How about when the child is exiting the program?***

To update the Parent/Child Form, the caseworker will complete a new Parent/Child Form. The caseworker goes over the client’s previous form with the original or most recently updated answers to each of the questions and asks, “is this still the case or has this changed?” The answers on the original/previous form(s) are not erased or overwritten. There is a place on the form to indicate whether it is an initial completion or an update.

PARENT/CHILD FORM: GENERAL INFORMATION

- 1. Question 7 – Reason for Update:***

When a change in the child's custody has occurred, the new primary caregiver reports becomes the Primary Participant. What about a child in foster care whose mother is still a HS client working a plan for reunification with child. There is no contact between Healthy Start and the foster parent regarding the child. The mother may have information about the child and having visitation. How is that documented? Is the child's case closed or can it remain open?

The child’s case can remain open with the mother serving as the Primary Participant providing the child’s information. If it is determined that the mother does not know enough about the child’s life in foster care, the program may wish to skip completing the Parent/Child Form. The program should determine the best approach on a case-by-case basis.

- 2. Question 8 – Update this form when this child exits HS:***

Please define "exit" with regard to using the forms. Is this only program completion (baby turned 18 months) or early exit from the program? If early exit is included as well, often times, this occurs because the participant is "lost to follow up" and no contact has been made in 60 days.

Yes, if possible, an update should occur when the baby exits the program, whether that is on program completion or early exit. We understand that sometimes clients leave abruptly and are “lost to follow up,” and that it is not always possible to get an exit interview or update the relevant forms.

- 3. Question 10 – Based on date of birth in box above, child is currently:***

Does this reference DOB at top of first page that is not reported to HRSA? Is this the age of the child at enrollment or is it changed with each update?

Yes, “date of birth in box above” references the DOB at the top of the first page in the grey box that is not reported to HRSA. At intake/original completion, this will reflect the child’s age at intake/initial enrollment. For an update, this will reflect the child’s age at the time of the update.

- 4. Question 11 – This child was enrolled in HS but then died: “Within 0 to 27 days of life”:**
If the child is born alive but dies within hours or days of birth, do we complete this form given the above instructions that this form should only be completed with participants who have “a (live) child enrolled in HS”?

The Parent/Child Form is not completed for infants who have died. Should the newborn have been enrolled in the program during the neonatal period (within 0 to 27 days of life), and have had a Parent/Child Form completed during that time, but then died afterward, the caseworker would update only Questions 7 and 11 of the General Information portion on pages 2 and 3 of the Parent/Child Form.

PARENT/CHILD FORM: ENROLLED CHILD GENERAL INFORMATION

- 1. Question 1 – Was your child: “Receiving HS services before birth”:**
Please confirm if this option is applicable to custodial fathers who are primary participants. On the other hand, if a pregnant woman is the primary participant during the pregnancy but decides to leave the program prior to delivery or upon delivery, whereas her accompanying adult (e.g., a father) decides to stay, which option would we choose when filling this out with dad?

“Receiving HS services before birth” would typically apply to a child born to an enrolled pregnant woman or to a father who is enrolled in the program as a primary participant at the time of birth. However, in the second scenario mentioned here, if the mother left the program after birth, it would be appropriate to say that the infant was “receiving HS services before birth” if the father decided to enroll into the program. The child cannot be enrolled in the program without a primary participant.

PARENT/CHILD FORM: INFANT HEALTH CARE

- 2. Question 12 – During the past 12 months, was this child EVER covered by any kind of health insurance or health insurance plan?**
For babies less than a year old, assume we use the “covered all 12 months” option?

Yes, if the baby had uninterrupted health insurance. Otherwise, select “Yes, but this child had a gap in coverage.”

- 3. Question 14 – How old was this child at his/her last well-child check-up?**
Question 14a – Was this child’s last well-child visit within the time frame recommended for this child’s age?
How should the child’s age be calculated? Current age at the time Parent/Child Form was completed?

Yes, use the child’s current age at the time the form is being completed or updated. At intake/original completion, this will reflect the child’s age at intake/initial enrollment. For an update, this will reflect the child’s age at the time of the update.

- 4. Question 14 – How old was this child at his/her last well-child check-up?**
Question 14a – Was this child’s last well-child visit within the time frame recommended for this child’s age?
Can you please provide guidance on how to determine if the child was in the recommend time frame for a well-child visit?

Compare the child's current age with the age at his/her last well-visit, and then compare these to the AAP recommended schedule of well-visits for the first 18 months of life (included in the Parent/Child Form). For example, an 11 month old should have had her 9 month well visit.

PARENT/CHILD FORM: INFANT FEEDING

1. ***Question 15 – Did you [or the biological mother] ever breast feed or pump breast milk to feed this child after delivery, even for a short period of time?***

If the biological mother did not breastfeed baby due to maternal death or other circumstances but baby has received breastmilk, what answer should we choose?

If the baby ever received breastmilk, answer yes.

2. ***Question 17 – How many months [up till current date] was this child breastfed or fed pumped milk?***

If a mother is breastfeeding, but the infant is under one month old, how should case managers document? For example, it looks like mothers who are still breastfeeding should document the number of months but what if the infant is not yet a month old, should they round up?

Select "less than one month." This response can be updated at the next phase change/update (e.g., when the infant is 6 months old).

PARENT/CHILD FORM: INFANT SLEEP

1. ***Question 20 – In the past 2 weeks, how often has your baby slept alone in his or her own crib or bed?***

For a participant who has a newborn baby enrolling in the program (whether born into it or enrolling soon after birth), would you recommend holding off on doing this form until the child is at least 2 weeks of age?

No, attention should be given to the health of the mother and the baby when scheduling the first visit after birth. If the baby is less than 2 weeks of age, base the response on the sleep practices up until that point. For example, if the baby is 10 days old, use that time frame as the basis for the response.

AGGREGATE REPORT/REPORTING

1. ***I believe there is an error in the form that we use for our monthly Aggregate Data. The formula for column totals (line 18) has the range: row 9-17. This means that the data for the months of Jan, Feb and Mar are not included in the total. I have (twice) sent this message to the Healthy Start Data email, but have not gotten a response.***

A revised template will be shared with the grantees shortly. [Thank you for the notification.]

2. ***When are we required to start submitting reports for data collected using the 3 new forms starting April 1, 2020 and ongoing? We do not have our database updated to input information for the 3 new forms yet. All screenings done with the new forms are currently saved on paper until the database is ready.***

Please see the timeline at the top of this document. Data reporting via HSMED2 will begin in mid-October 2020.

- 3. YTD section: do we count all participants who are open at that time, or do we count participants who have actually received services? In the early months of the year, we have "open" participants who have not received services yet this year, and some of them will end up being lost to follow-up and never receiving any services this year. Currently we only count those who have received services.***

Only those who have received services are counted.

OTHER

- 1. With the new tools implementation, what is the reason for keeping the "Encounter additional info & observation form? If we are keeping it, what info/boxes are required to fill out?***

This is a question specific to the database at the grantee site.

- 2. How are we filling out the risk factor tab form? From the client/caregiver substance abuse screening or will this be eliminated?***

This is a question specific to the database at the grantee site.