Data Use and Non-Disclosure Agreement

Between

[Vital Records Office, Jurisdiction Health Agency]

and

[Healthy Start Grantee(s)]

and

Maternal and Child Health Bureau, Health Resources and Services Administration

This data use and non-disclosure agreement (“Agreement”) is between the [Vital Records Office, Jurisdiction Health Agency] (“Jurisdiction VRO”), Healthy Start Grantee(s) (“HS Grantee(s)”), and the Maternal and Child Health Bureau of the Health Resources and Services Administration (“MCHB”), for the purposes described below. HS Grantee(s), MCHB and the Jurisdiction VRO may be individually referred to herein as “Party” or collectively as “Parties.”

The Jurisdiction VROcollects, owns and maintains certain birth and death records and related data elements for births and linked infant deaths occurring within the Jurisdiction VRO’s geographic jurisdiction. All HS Grantees are expected to participate in the national evaluation of Healthy Start. In order for a HS Grantee to participate in this evaluation, it must seek the informed consent of HS Grantee participants to allow the HS Grantee(s) to provide certain personally identifiable data (Linkage Variables) to the Jurisdiction VRO in order for the VRO to link with vital records (birth and linked infant death) information so that pregnancy outcome information from vital records can be used in the national Healthy Start evaluation.

In connection with this Agreement and pursuant to the terms and conditions set forth herein, the Jurisdiction VRO desires to permit MCHB and other Authorized Users (defined below) to receive transmission of selected data elements from birth and infant death records as described below solely for the purposes stated herein (the “Project”).

Parties agree to the following:

**1. Purpose.** The purpose of this Agreement is to clearly describe and obtain agreement of the signing Parties to the specific HS Grantee Linkage Variables and Instructions, as defined below, to be provided by the HS Grantee(s) to the Jurisdiction VRO, and Data, as defined below, so that the Jurisdiction VRO can provide such Data to MCHB. In addition, this agreement sets forth the intended uses of the Linkage Variables and the Data, and the conditions under which the Linkage Variables and the Data are provided, as well as all limitations on access to and use and release of Linkage Variables and Data and any Data products.

**2. Description of Data**. The Linkage Variables mean personally identifiable information identified in Exhibit A provided by the HS Grantee(s) to the VRO in order to obtain linkage with vital records. The data (“Data”) means the elements identified in Exhibit B for selected births and infant deaths occurring in such state or jurisdiction represented by the Jurisdiction VRO in 2017 that will be provided to MCHB.

**3. Scope of the Agreement.** Under this agreement, the VRO will receive from designated HS Grantee(s) in their jurisdiction the Linkage Variables on selected 2017 Healthy Start participants who have consented to be included in the national Healthy Start Evaluation. The VRO will use the Linkage Variables to link with information provided on the birth and infant death records associated with these Healthy Start participants and provide the vital records data elements (see Exhibit B) to MCHB for the purposes of the national Healthy Start evaluation, which may, in some jurisdictions, include a PRAMS oversample. The VRO may, if it wishes, and a HS grantee in their state so requests, also provide the vital records data to the requesting Healthy Start grantee as an Authorized User, but any such agreement to do so is outside the scope of this agreement, unless this agreement is amended to incorporate this additional data use.

In addition, the VRO will also provide to MCHB de-identified individual case record data for all other 2017 births and their linked infant deaths in the county or counties served by the Healthy Start grantee(s) so that MCHB can select matched controls for the national evaluation. These de-identified data should include all variables specified in Exhibit B; Healthy Start UniqueID and date of enrollment will be blank as these data represent non-participants.

**4. Representation of Authority**. Jurisdiction VRO [reference supplied by each jurisdiction to its authority to provide data to government agencies for approved purposes]

The authorities for MCHB and the HS Grantee(s) are 42 USC § 254c-8(e)(2)(B), in the Healthy Start statute.

**5. Right to Use Data; Ownership.**

1. The HS Grantee(s) grants to the Jurisdiction VRO a non-exclusive and non-transferable right to receive the Linkage Variables and to use them solely for the purposes expressly authorized herein during the Term of this Agreement. No other use is granted under this Agreement.

b. The Jurisdiction VRO grants to MCHB and Authorized Users a non-exclusive and non-transferable right to access the Data and to use it solely for the purposes expressly authorized herein during the Term of this Agreement. No other use is granted under this Agreement except as permitted under item 3 above relative to external agreements between the VRO and an individual Healthy Start grantee.

c. At all times throughout the term of this Agreement and after its termination, each Jurisdiction VRO shall maintain ownership of the Data it makes available in connection with this Agreement. Other than as is expressly stated in this Agreement, nothing herein grants MCHB, any Authorized User or any third party any rights, title or interest in such Data except to the extent required by Federal law.

**6. Permitted Uses of Data.**

**a.** MCHB may use the vital records data provided by the jurisdiction VRO solely for the purpose of conducting the national Healthy Start evaluation.

**b.** Any other use of or access to the Data by MCHB or any other Authorized User will require prior written authorization by the Jurisdiction VRO.

**7. Limitations on Data Use.**

**a.** MCHB shall not link or attempt to link, nor permit others to attempt to link the Data with individual records from any other data set except the Healthy Start participant screening tools, without the prior written approval of the Jurisdiction VRO.

**b.** MCHB shall not use the Data or allow anyone else to use the Data for purposes of attempting to learn the identity of any person without the prior written approval of the Jurisdiction VRO.

**c.** Other than as expressly stated in this Agreement, MCHB shall not use, copy, modify, make derivative works of, release, disseminate or disclose Jurisdiction VRO-provided Data to any third party for any purpose without prior written approval of the Jurisdiction VRO unless required by Federal law.

**8. Data Transmission Schedule and Fees.**

**a.** Upon acceptance by MCHB of the signed data agreement(s), the Jurisdiction VRO will invoice National Center for Health Statistics (NCHS) for payment under Special Project 2 of the 2016 VSCP contract, in accordance with the Fee Schedule in Exhibit C.

**b.** The Healthy Start grantee(s) shall transmit Linkage Variables to the Jurisdiction VRO in a format and according to a mechanism specified by the Jurisdiction VRO, in accordance with the Data transmission schedule in Exhibit D.

**c.** The Jurisdiction VRO shall transmit Data to MCHB in the file format specified in Exhibit B via [what mechanism?] in accordance with the Data transmission schedule in Exhibit D.

**9. Authorization of Users**.

As used herein, the term “Authorized Users” shall include:

**a.** those individuals or entities specifically granted permission by MCHB, including but not limited to MCHB staff and specified MCHB contractors solely to support the Project as described herein;

**b.** designated Healthy Start grantee(s) staff if approved by the Jurisdiction VRO under a separate agreement.

**10. Data Retention.**

**a.** The Jurisdiction VRO will destroy Linkage Variables received from the HS grantee at the conclusion of the national Healthy Start evaluation project consistent with Jurisdiction records retention requirements.

**b.** MCHB will destroy all data provided by the Jurisdiction VRO at the conclusion of the national Healthy Start evaluation project to the extent consistent with Federal records retention requirements.

**11. Confidentiality and Data Security:**

The confidentiality of all Data provided by the jurisdiction VRO to MCHB under this agreement is protected under the Privacy Act, 5 U.S.C. § 552a. MCHB and all other Authorized Users with approved access to Data under this Agreement shall take all reasonable physical, technical and administrative measures to safeguard and keep the Data confidential and secure, including, but not limited to:

**a.** Storing Data in secure access-restricted files;

**b.** Encrypting any laptop, USB, CD or other mobile storage tool, device, or equipment used to store and/or transmit Data;

**c.** Using a password or encryption system to obtain and restrict Data access only to Authorized Users specified in this Agreement;

**d.** Keeping any hardcopy versions of files containing Data in locked areas with restricted access and ensuring that unauthorized persons do not have access to such locked areas;

**e.** Ensuring that only Authorized Users shall have access to Data;

**f.** Providing a firewall to protect Data from any unauthorized user.

Copies of approved data security policies and demonstration that employees are aware of, and required to operate under, these policies will be provided if requested under a data security assessment or data security audit.

**12. Unauthorized or Inadvertent Use or Disclosure.**

**a.** MCHB shall report to the Jurisdiction VRO in writing any unauthorized use or disclosure of the Data (whether inadvertent or intentional) in violation of this Agreement, including in such report the (i) recipient and transmitter of such Data, (ii) the date of the unauthorized use or disclosure, (iii) the name and address (if known) of the user or recipient, (iv) a brief description of the information used or disclosed, (v) any remedial measures taken to retrieve or otherwise repossess such information or other measures to mitigate the use or further disclosure of such information and (vi) all other details concerning the unauthorized or inadvertent use or disclosure and the resulting mitigating steps being taken or recommended by NCHS as are requested by the Jurisdiction VRO. Initial notification shall be made by MCHB to the Jurisdiction VRO within three (3) business days after MCHB becomes aware of the unauthorized use or disclosure. MCHB agrees to fully cooperate with any investigation conducted by the Jurisdiction VRO or its agent of any such unauthorized use or disclosure.

**b.** If the identity of any decedent is discovered inadvertently as a result of MCHB’s access to the Data, MCHB will not make use of this knowledge; MCHB will immediately notify the Jurisdiction VRO and will safeguard or destroy the information which led to the identification of the individual, as requested by the Jurisdiction VRO.

**c.** MCHB shall be responsible for any breach of data security leading to the unauthorized disclosure or use of the Data. It is the intent of the parties that the Jurisdiction VRO will not be liable for any use or disclosure of the Data by MCHB, its employees, agents, and/or contractors, or for any claims, damages, losses, or liabilities, of whatsoever kind or nature, which may arise out of or in connection with the use or disclosure of the Data by MCHB, its employees, agents, and/or contractors. Penalties for unauthorized disclosure are stipulated in the Privacy Act, 5 U.S.C. § 552a.

**13. Term and Termination of Agreement.**

**a. Term.** This Agreement is effective upon the date of the last signatory hereto (the “Effective Date”) and will continue until the completion of all performance obligations hereunder, unless terminated earlier in accordance with this Section (the “Initial Term”). This Agreement may be renewed by written agreement of the Parties for additional terms (each, a “Renewal Term”) (the Initial Term and Renewal Term(s) shall collectively be referred to as the “Term”).

**b. Termination for cause**. Either Party may terminate this Agreement immediately upon material breach of the agreement by the other Party.

**c. Termination without cause**. Either Party may terminate this Agreement without cause by giving the other Party at least 30 days advance written notice of intent.

**d. Effect of Termination.**  MCHB will either destroy or return to the Jurisdiction VRO all Data provided by the Jurisdiction VRO.

**e. Survival.** Upon the termination of this Agreement for any reason, the confidentiality provisions set forth herein shall continue to apply to the Data shared with MCHB or other Authorized Users pursuant to this Agreement.

**14. Disputes.** The Parties shall use their best efforts to resolve any dispute between the Parties arising under this Agreement through face-to-face good faith negotiations. Disputes not resolved within sixty (60) days following notice of the dispute shall be resolved by either party seeking a judicial remedy in a court of competent jurisdiction.

**15. Notices**. Notices given by the Parties to one another in connection with this Agreement shall be in writing and delivered by hand delivery, return mail, by email with appropriate confirmation of receipt, or by nationally-recognized express delivery service to the Parties’ respective addresses set forth below or to such other address as the Parties may substitute by giving notice to one another in accordance with this Section. Notices shall be deemed to have been received upon the earlier of actual receipt thereof, or, with respect to (a) overnight delivery, by the next business day following delivery to such express delivery service, (b) U.S. mail, by the third business day following such delivery to the U.S. Postal Service.

Designated Representative of MCHB:

Name:

Title:

Telephone:

Address:

Email:

Designated Representative of HS Grantee(s):

Name:

Title:

Telephone:

Address:

Email:

Designated Representative of Jurisdiction VRO:

Name:

Title:

Telephone:

Address:

Email:

**16. Publication.** Jurisdiction VROs require acknowledgment of the Data they provided to MCHB in any publication, report, poster, talk, news release, web page, or other presentation or use (print, or electronic) developed from the Data provided by jurisdiction VROs or describing the Project or results of the Project by MCHB, its staff, contractors, or other Authorized Users of the Data.

**17. Information Disclaimer**. The Parties agree that any Data received or accessed by MCHB or an Authorized User may be transmitted from the Jurisdiction VRO without being first reviewed or verified by Jurisdiction VRO. Data that is received or transmitted pursuant to this Agreement is provided on an “as is, where is,” basis, meaning it is maintained and transmitted by the Jurisdiction VRO without any guarantee or warranty whatsoever (including, but not limited to), as to its completeness, accuracy or reliability.

**18. Binding Nature and Assignment.** This Agreement shall be binding upon and inure to the benefit of the Parties hereto and their successors and assigns.

**19. Governing Law.** This Agreement shall be interpreted and construed in accordance with Federal law as administered in the state or jurisdiction represented by the Jurisdiction VRO.

**20. Force Majeure**.Neither Party shall be liable for any failure or delay in performing all or part of its obligations under the terms of this Agreement caused by or resulting from, legislative action or other acts of government, war, acts of any person engaged in a subversive activity, sabotage, riots, strikes, slow-downs, lock-outs, or labor stoppage, freight embargoes, fires, explosions, flood, earthquake or other acts of God, or by reason of the judgment, filing or order of any court or agency of competent jurisdiction occurring subsequent to the signing of this Agreement, unavailability of data, fiber cut caused by a third Party or any other circumstances reasonably beyond a Party’s control (a “Force Majeure Event”).

**21. Entire Understanding and Modification.** This Agreement contains all of the terms and conditions agreed upon by the Parties related to the Project, and supersedes all prior understandings, writings, proposals, representations, or communications, oral or written, of the Parties hereto as to the subject matter addressed herein. Each Party represents and warrants that any changes to this Agreement made by a Party prior to execution were clearly marked as changes and that it made no changes to this Agreement that were not properly and clearly marked as changes to this Agreement. After execution, this Agreement may not be modified, amended or changed except by a written Agreement signed by the Parties.

**22. No Implied Waiver.** Except as expressly provided herein, the failure of either Party to insist, in any one or more instances, upon the performance of any provision of this Agreement shall not be construed as a waiver or a relinquishment of any right granted or arising hereunder or of the future performance of any such provision. Such failure shall in no way affect the validity of this Agreement or the rights and obligations of the Parties hereunder.

**23. Relationship of Parties.** This Agreement shall not constitute or otherwise imply a joint venture, partnership or formal business organization of any kind. Both Parties shall be considered independent contractors and neither Party shall be considered an agent, designee or representative of the other for any purpose. Under no circumstances shall employees of one Party be deemed the employees of the other Party.

**24. Survival.** The Parties’ respective representations, warranties and covenants, together with Section 12 and the obligations of confidentiality and limitations on liability will survive the expiration, termination or rescission of this Agreement and shall continue in full force and effect.

**25. Severability.** Shouldany part, term or condition of this Agreement be declared illegal, invalid or unenforceable or in conflict with any other laws, the remaining provisions shall be valid and not affected thereby.

**26. Headings.** The headings in this Agreement are strictly for convenience and do not amplify or limit any of the terms, provisions or conditions contained herein.

**27. No Third Party Beneficiary Rights.**  Except as otherwise expressly provided in this Agreement, nothing in this Agreement shall be enforceable by any person other than the parties hereto, and no third Party beneficiary rights are conferred on any such third Party.

**28. Counterparts.** This Agreement may be executed in any number of counterparts, each of which shall be deemed an original and all of which taken together shall constitute one and the same instrument.

**[Signatures appear on following page]**

The undersigned warrant that they are authorized representatives of their respective Party and that they have full power and authority to enter into this Agreement and bind their respective Party to its terms and, in the case of a Jurisdiction VRO, to its applicable State terms.

[HS Grantee]:

By:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Name:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Title:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Date:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

[HS Grantee]:

By:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Name:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Title:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Date:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

[Jurisdiction VRO]:

By:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Name:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Title:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Date:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

[MCHB]:

By:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Name:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Title:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Date:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**EXHIBIT A**

**Healthy Start Linkage Instructions and Linkage Variables**

* Collect as many individual identifiers as possible from the list of participants below (**bold** are required):

1. Every pregnant woman served in calendar year 2017 and beyond with informed consent (also include any served in 2016 with a known or expected delivery date in 2017)
2. Any postpartum woman served in calendar year 2017 and beyond that delivered in 2017 and beyond with informed consent (postpartum enrollees will serve as an important internal comparison group)

The greater the detail that is collected, the greater is the likelihood of successful linkage to vital records.

* Track consent rates for participation in the evaluation; consent rates will be monitored by a HRSA contractor who can provide technical assistance where possible

Individual Identifiers (Linkage Variables)

* **Mother’s name\* (in separate fields for first, middle, last, maiden)**
* **Mother’s date of birth (or age in years but exact date of birth is preferred)**
* Mother’s address at time of delivery (street, city, zip code, county)
* Mother’s social security number
* Mother’s race
* Mother’s ethnicity
* Mother’s Medicaid status (yes/no)
* Mother’s gravidity (# previous pregnancies)
* Mother’s parity (# previous live births)
* Mother’s date of enrollment
* **Mother’s Unique Client ID #** that can be used to anonymously identify the HS participant and subsequently link back to any client-level information (e.g., 3Ps) that is provided to HRSA
* **Infant date of birth\* (or expected month, day and year of delivery if unknown)**
* Infant birth hospital\*
* Infant sex\*
* Infant name (in separate fields for first, last)\*
* Infant birthweight in grams\*

**Bold** = required elements

\*May not be available if participant is lost to follow-up (e.g., moves, stops participating, etc.) or has not yet delivered; linkage will be attempted regardless of the number of available individual identifiers.

**EXHIBIT B**

**DATA FILE FORMAT**

#### Coding specifications for state/jurisdiction Vital Records Offices

| **Table A1. Variables from the Birth Certificate (2003 revision)**  **White rows are part of the standard PRAMS file (Columns 1-168)**  **Peach rows are additional HS participant identifiers (Columns 169-198)**  **Light Blue rows are additional requested variables from the birth certificate (Columns 199-232; to be appended to PRAMS file based on Birth Certificate or State ID #)** | | | |
| --- | --- | --- | --- |
| **Variable Name** | **Variable Label** | **Codes** | **Column** |
| BC | Birth Certificate Number | 000000000001 B 999999999999  Right aligned | 1-12 (12) |
| SEX | Gender of Infant | 1 = male  2 = female  9 = not yet determined | 13 (1) |
| MM\_DOB | Month of Birth | 01-12 = month  99 = unknown | 14-15 (2) |
| DD\_DOB | Day of Birth | 01-31 = day  99 = unknown | 16-17 (2) |
| YY4\_DOB | Year of Birth | current year = year | 18-21 (4) |
| POB | Place of Birth | 1 = hospital  2 = birth center  3 = clinic/medical office  4 = residence (includes all home births)  5 = other  9 = unknown | 22 (1) |
| HOSP\_NUM | Hospital of Birth | 00000-99990 = hospital  Number defined by each state  99999 = unknown | 23-27 (5) |
| MM\_MDOB | Mother’s Month of Birth | 01-12 = month  99 = unknown | 28-29 (2) |
| DD\_MDOB | Mother’s Day of Birth | 01-31 = day  99 = unknown | 30-31 (2) |
| YY4\_MDOB | Mother’s Year of Birth | (child’s year of birth - 60) through (child’s year of birth - 11) = year  9999 = unknown | 32-35 (4) |
| MAT\_AGE | Maternal Age | Calculated, in years  99 = unknown  **Note:** This variable is calculated by taking Date of child’s birth - Date of Mother’s birth. If either of these values are unknown then variable is coded “unknown”. | 36-37 (2) |
| MOM\_RES | Maternal County of Residence | Number defined by each state  000-990 = county  999 = unknown | 38-40 (3) |
| EVER\_MAR | Ever Married | 1 = yes  2 = no  9 = unknown | 41 (1) |
| MARRIED | Marital Status | 1 = yes  2 = no  9 = unknown | 42 (1) |
| PAT\_ACK | Acknowledgment of Paternity | 1 = yes  2 = no  8 = not applicable  9 = unknown | 43 (1) |
| MAT\_DEG | Maternal Highest Degree Received | 1 = ≤ 8th grade  2 = 9-12 grade, no diploma  3 = High School Graduate/GED  4 = Some College, No degree  5 = Associate Degree  6 = Bachelor’s Degree  7 = Master’s Degree  8 = Doctorate or Professional Degree  9 = unknown | 44 (1) |
| MAT\_ED | Maternal Years of Education | 1 = 0-8 years (≤ 8th grade)  2 = 9-11 years (9-12 grade, no diploma)  3 = 12 years (High School Graduate/GED)  4 = 13-15 years (Some College or Associate Degree)  5 = 16 or more years (Bachelor’s Degree or higher)  9 = unknown | 45 (1) |
| PAT\_DEG | Paternal Highest Degree Received | 1 = ≤ 8th grade  2 = 9-12 grade, no diploma  3 = High School Graduate/GED  4 = Some College, No degree  5 = Associate Degree  6 = Bachelor’s Degree  7 = Master’s Degree  8 = Doctorate or Professional Degree  9 = unknown | 46 (1) |
| PAT\_ED | Paternal Years of Education | 1 = 0-8 years (≤ 8th grade)  2 = 9-11 years (9-12 grade, no diploma)  3 = 12 years (High School Graduate/GED)  4 = 13-15 years (Some College or Associate Degree)  5 = 16 or more years (Bachelor’s Degree or higher)  9 = unknown | 47 (1) |
| HISP\_BC | Mother Hispanic? | 1 = yes  2 = no  9 = unknown | 48 (1) |
| FHISP\_BC | Father Hispanic? | 1 = yes  2 = no  9 = unknown | 49 (1) |
| MRACE\_WHT | Mother’s Race - White | 1 = yes  2 = no | 50 (1) |
| MRACE\_BLK | Mother’s Race - Black | 1 = yes  2 = no | 51 (1) |
| MRACE\_AMI | Mother’s Race - American Indian or Alaska Native | 1 = yes  2 = no | 52 (1) |
| MRACE\_ASI | Mother’s Race - Asian Indian | 1 = yes  2 = no | 53 (1) |
| MRACE\_CHN | Mother’s Race - Chinese | 1 = yes  2 = no | 54 (1) |
| MRACE\_FLP | Mother’s Race - Filipino | 1 = yes  2 = no | 55 (1) |
| MRACE\_JPN | Mother’s Race - Japanese | 1 = yes  2 = no | 56 (1) |
| MRACE\_KOR | Mother’s Race - Korean | 1 = yes  2 = no | 57 (1) |
| MRACE\_VTM | Mother’s Race - Vietnamese | 1 = yes  2 = no | 58 (1) |
| MRACE\_ASO | Mother’s Race - Other Asian | 1 = yes  2 = no | 59 (1) |
| MRACE\_NHW | Mother’s Race - Native Hawaiian | 1 = yes  2 = no | 60 (1) |
| MRACE\_GAM | Mother’s Race - Guamanian or Chamorro | 1 = yes  2 = no | 61 (1) |
| MRACE\_SAM | Mother’s Race - Samoan | 1 = yes  2 = no | 62 (1) |
| MRACE\_PIO | Mother’s Race - Other Pacific Islander | 1 = yes  2 = no | 63 (1) |
| MRACE\_OTH | Mother’s Race - Other | 1 = yes  2 = no | 64 (1) |
| MAT\_RACE | Maternal Race | 0 = Other Asian or Pacific Islander  1 = White  2 = Black  3 = American Indian  4 = Chinese  5 = Japanese  6 = Filipino  7 = Hawaiian  8 = Other Race  9 = unknown  A = Alaska Native  B = Multiple Race | 65 (1) |
| FRACE\_WHT | Father’s Race - White | 1 = yes  2 = no | 66 (1) |
| FRACE\_BLK | Father’s Race - Black | 1 = yes  2 = no | 67 (1) |
| FRACE\_AMI | Father’s Race - American Indian or Alaska Native | 1 = yes  2 = no | 68 (1) |
| FRACE\_ASI | Father’s Race - Asian Indian | 1 = yes  2 = no | 69 (1) |
| FRACE\_CHN | Father’s Race - Chinese | 1 = yes  2 = no | 70 (1) |
| FRACE\_FLP | Father’s Race - Filipino | 1 = yes  2 = no | 71 (1) |
| FRACE\_JPN | Father’s Race - Japanese | 1 = yes  2 = no | 72 (1) |
| FRACE\_KOR | Father’s Race - Korean | 1 = yes  2 = no | 73 (1) |
| FRACE\_VTM | Father’s Race - Vietnamese | 1 = yes  2 = no | 74 (1) |
| FRACE\_ASO | Father’s Race - Other Asian | 1 = yes  2 = no | 75 (1) |
| FRACE\_NHW | Father’s Race - Native Hawaiian | 1 = yes  2 = no | 76 (1) |
| FRACE\_GAM | Father’s Race - Guamanian or Chamorro | 1 = yes  2 = no | 77 (1) |
| FRACE\_SAM | Father’s Race - Samoan | 1 = yes  2 = no | 78 (1) |
| FRACE\_PIO | Father’s Race - Other Pacific Islander | 1 = yes  2 = no | 79 (1) |
| FRACE\_OTH | Father’s Race - Other | 1 = yes  2 = no | 80 (1) |
| PAT\_RACE | Paternal Race | 0 = Other Asian or Pacific Islander  1 = White  2 = Black  3 = American Indian  4 = Chinese  5 = Japanese  6 = Filipino  7 = Hawaiian  8 = Other Race  9 = unknown  A = Alaska Native  B = Multiple Race | 81 (1) |
| MAT\_TRAN | Mom Transferred? | 1 = yes  2 = no  9 = unknown | 82 (1) |
| MM\_LMP | Month of Last Menstrual Period | 01-12 = month  99 = unknown | 83-84 (2) |
| DD\_LMP | Day of Last Menstrual Period | 01-31 = day  99 = unknown | 85-86 (2) |
| YY4\_LMP | Year of Last Menstrual Period | yr of child’s birth or (yr of child’s birth-1) or (yr of child’s birth-2) = yr  9999 = unknown | 87-90 (4) |
| MM\_PCV | Month of First Prenatal Care Visit | 01-12 = month  88 = no care  99 = unknown | 91-92 (2) |
| DD\_PCV | Day of First Prenatal Care Visit | 01-31 = day  88 = no care  99 = unknown | 93-94 (2) |
| YY4\_PCV | Year of First Prenatal Care Visit | yr of child’s birth or (yr of child’s birth - 1) = year  8888 = no prenatal care  9999 = unknown | 95-98 (4) |
| PNC\_MTH | Month of First Prenatal Care Visit | 01-09 = month  88 = no prenatal care  99 = unknown  **Note:** This variable is calculated using the Date of Last Menstrual Period and the Date of First Prenatal Care Visit. If either of these values are unknown then variable is coded “unknown”. | 99-100 (2) |
| PNC\_VST | Number of Prenatal Care Visits | 00-98 = number of visits  99 = unknown | 101-102 (2) |
| MAT\_HTFT | Mother’s Height - Feet | 1-8 = feet  9 = unknown | 103 (1) |
| MAT\_HTIN | Mother’s Height - Inches | 00-11 = inches  99 = unknown | 104-105 (2) |
| MAT\_PRWT | Mother’s Weight - Prepregnancy | 050-400 = lbs  999 = unknown | 106-108 (3) |
| MAT\_DLWT | Mother’s Weight - At Delivery | 050-450 = lbs  999 = unknown | 109-111 (3) |
| MOMLBS | Maternal Weight Gain | Calculated in pounds (lbs.)  00 = weight loss/no gain  01-96 = number gained  97 = 97 or more gained  99 = unknown  **Note:** This variable is calculated by taking Weight at Delivery - Weight Prepregnancy. If either of these values are unknown then variable is coded “unknown”. | 112-113 (2) |
| MAT\_WIC | Mother get WIC Food during Pregnancy? | 1 = yes  2 = no  9 = unknown | 114 (1) |
| MOMSMOKE | Did Mom Smoke during Pregnancy? | 1 = yes  2 = no  8 = not recorded  9 = unknown  **Note:** This variable is coded “yes” if Mom smoked in any of the three trimesters. | 115 (1) |
| CIG\_PRIOR | No. of Cigarettes Smoked - Prior to Pregnancy | 00-98 = number per day  99 = unknown | 116-117 (2) |
| CIG\_1TRI | No. of Cigarettes Smoked - 1st Trimester | 00-98 = number per day  99 = unknown | 118-119 (2) |
| CIG\_2TRI | No. of Cigarettes Smoked - 2nd Trimester | 00-98 = number per day  99 = unknown | 120-121 (2) |
| CIG\_3TRI | No. of Cigarettes Smoked - 3rd Trimester | 00-98 = number per day  99 = unknown | 122-123 (2) |
| MOMCIG | No. of Cigarettes Smoked during Pregnancy | 00-98 = number per day  99 = unknown  **Note:** This variable is calculated by finding the average of the No. of Cigs in 1st Trimester, No. of Cigs in 2nd Trimester, and No. of Cigs in 3rd Trimester. If any of these 3 values is unknown then variable is coded “unknown”. | 124-125 (2) |
| PAY | Principal Source of Payment for this Delivery | 1 = medicaid  2 = private insurance  3 = self-pay  4 = Indian health service  5 = champus/tricare  6 = other gov. (Fed, State, Local)  8 = other  9 = unknown | 126 (1) |
| PRE\_LB | Number of Previous Live Births | As recorded  99 = unknown | 127-128 (2) |
| MM\_LLB | Month of Last Live Birth | -1 = first live birth  01-12 = month  99 = unknown | 129-130 (2) |
| YY4\_LLB | Year of Last Live Birth | -1 = first live birth  (Mother’s yr of birth + 10) through (child’s yr of birth) = year  9999 = unknown | 131-134 (4) |
| OTH\_TERM | Previous Other Pregnancy Outcomes | 00-30 = number of other outcomes  99 = unknown | 135-136 (2) |
| MM\_DIAB | Gestational Diabetes? | 1 = yes  2 = no  9 = unknown  **Note:** This variable is from the "Risk factors in this pregnancy (41)" section of the U.S. standard birth certificate. This variable is coded as “yes" if gestational diabetes is coded “Y”, it is coded as “no” if gestational diabetes is “N”, else it is coded “unknown”. | 137 (1) |
| MM\_HBP | Hypertension? | 1 = yes  2 = no  9 = unknown  **Note:** This variable is from the "Risk factors in this pregnancy (41)" section of the U.S. standard birth certificate. This variable is coded as "yes" if either prepregnancy hypertension or gestational hypertension is coded “Y”, it is coded as “no” if both are “N”, else it is coded “unknown”. | 138 (1) |
| P\_PRTERM | Previous Preterm Births | 1 = yes  2 = no  9 = unknown  **Note:** This variable is from the "Risk factors in this pregnancy (41)" section of the U.S. standard birth certificate. This variable is coded as “yes” if previous preterm birth is coded “Y”, it is coded as “no” if previous preterm birth is “N”, else it is coded “unknown”. | 139 (1) |
| INFER\_TR | Infertility Treatment | 1 = yes  2 = no  9 = unknown  **Note:** This variable is from the "Risk factors in this pregnancy (41)" section of the U.S. standard birth certificate. This variable is coded as "yes" if infertility treatment is coded “Y”, it is coded as “no” if infertility treatment is “N”, else it is coded “unknown”. | 140 (1) |
| MM\_NOMD | No Medical Risk Factors? | 1 = yes  2 = no  9 = unknown  **Note**: This variable is coded as "yes" if prepregnancy diabetes, gestational diabetes, prepregnancy hypertension, gestational hypertension, previous preterm births, poor pregnancy outcome, and vaginal bleeding are all coded “N”, it is coded as “no” if any are “Y”, else it is coded as “unknown”. | 141 (1) |
| MM\_PROM | Premature Ruptured Membrane? | 1 = yes  2 = no  9 = unknown  **Note:** This variable is from the "Onset of Labor (44)" section of the U.S. standard birth certificate. This variable is coded as "yes" if premature ruptured membrane is coded AY@, it is coded as Ano@ if premature ruptured membrane is AN@ , else it is coded Aunknown@. | 142 (1) |
| MM\_FEVER | Fever? (Chorioamnionitis) | 1 = yes  2 = no  9 = unknown  **Note:** This variable is from the "Characteristics of Labor and Delivery (45)" section of the U.S. standard birth certificate. This variable is coded as "yes" if chorioamnionitis is coded AY@, it is coded as Ano@ if chorioamnionitis is AN@ , else it is coded Aunknown@. | 143 (1) |
| DEL\_VAG | Vaginal Delivery? | 1 = yes  0 = no  9 = unknown  **Note**: This variable is coded as "yes" if (“Route & Method of Delivery” is coded “1”, “2”, or “3” and “Previous Cesarean” is coded “N”), it is coded as “no” if either (“Route & Method of Delivery” is coded “1”, “2”, or “3” and “Previous Cesarean” is coded “Y”) or (“Route & Method of Delivery” is coded “4”), else it is coded as “unknown”. | 144 (1) |
| DEL\_FORC | Forceps Delivery? | 1 = yes  0 = no  9 = unknown  **Note**: This variable is coded as "yes" if “Route & Method of Delivery” is coded “2", it is coded as “no” if “Route & Method of Delivery” is coded “1”, “3”, or “4”, else it is coded as “unknown”. | 145 (1) |
| DEL\_VACM | Vacuum Delivery? | 1 = yes  0 = no  9 = unknown  **Note**: This variable is coded as "yes" if “Route & Method of Delivery” is coded “3”, it is coded as “no” if “Route & Method of Delivery” is coded “1”, “2”, or “4”, else it is coded as “unknown”. | 146 (1) |
| DEL\_VCS | Vaginal Delivery After C-Section? | 1 = yes  0 = no  9 = unknown  **Note**: This variable is coded as "yes" if (“Route & Method of Delivery” is coded “1”, “2”, or “3” and “Previous Cesarean” is coded “Y”), it is coded as “no” if either (“Route & Method of Delivery” is coded “1”, “2”, or “3” and “Previous Cesarean” is coded “N”) or (“Route & Method of Delivery” is coded “4”), else it is coded as “unknown”. | 147 (1) |
| DEL\_1CS | First C-Section? | 1 = yes  0 = no  9 = unknown  **Note**: This variable is coded as "yes" if (“Route & Method of Delivery” is coded “4” and “Previous Cesarean” is coded “N”), it is coded as “no” if either (“Route & Method of Delivery” is coded “4” and “Previous Cesarean” is coded “Y”) or (“Route & Method of Delivery” is coded “1”, “2”, or “3”), else it is coded as “unknown”. | 148 (1) |
| DEL\_RCS | Repeated C-Section? | 1 = yes  0 = no  9 = unknown  **Note**: This variable is coded as "yes" if (“Route & Method of Delivery” is coded “4” and “Previous Cesarean” is coded “Y”), it is coded as “no” if either (“Route & Method of Delivery” is coded “4” and “Previous Cesarean” is coded “N”) or (“Route & Method of Delivery” is coded “1”, “2”, or “3”), else it is coded as “unknown”. | 149 (1) |
| GRAM | Birth weight | 227-8165 grams  9999 = unknown | 150-153 (4) |
| GEST\_WK | Obstetric Estimation of Gestation | As recorded, in weeks  99 = unknown | 154-155 (2) |
| PLURAL | Plurality | 1 = single  2 = twin  3 = triplet  9 = unknown  Note: quadruplet and higher order births not eligible for sampling | 156 (1) |
| B\_ORDER | Birth Order | 1 = first  2 = second  3 = third  4 = fourth  5 = fifth  etc... | 157 (1) |
| LIVE\_BORN | No. of Live Born | As recorded  9 = unknown | 158 (1) |
| MATCH | Matching Number | As recorded  000001-999999 | 159-164 (6) |
| DEFECT | Was the Baby Born With a Birth Defect? | 1 = yes  2 = no  9 = unknown  **Note**: This variable is coded as "yes" if any of the congenital anomalies are coded “Y” or “C”, it is coded as “no” if all are “N”, else it is coded as “unknown”. | 165 (1) |
| TRANS | Infant Transferred? | 1 = yes  2 = no  9 = unknown | 166 (1) |
| ALIVE | Infant Living at time of report? | 1 = yes  2 = no  9 = transferred, status unknown | 167 (1) |
| BRSTFED | Infant being Breast-fed? | 1 = yes  2 = no  9 = unknown | 168 (1) |
| HS\_ID | HS Participant ID Number | Store as a character variable with a max of 50 characters; leave blank if not an HS participant | 169-218 (50) |
| DENROLL | Date of HS enrollment | MMDDYYYY; leave blank if not an HS participant | 219-228 (10) |
| STATE | State of Residence | State FIPS | 229-230 (2) |
| ZIPCODE | ZIP code of Residence |  | 231-235 (5) |
| CTRACT | Census tract of Residence | Leave blank if unavailable | 236-241 (6) |
| STATE\_O | State of Occurrence | State FIPS | 242-243 (2) |
| COUNTY\_O | County of Occurrence | County FIPS | 244-246 (3) |
| MBSTATE\_REC | Mother’s Nativity | 1=Born in the U.S. (50 US States)  2=Born outside the U.S. (includes possessions)  3=Unknown or Not Stated | 247 (1) |
| MHISP\_R | Mother’s Hispanic Origin Recode | 0 = Non-Hispanic  1 = Mexican  2 = Puerto Rican  3 = Cuban  4 = Central and South American  5 = Other and Unknown Hispanic origin  9 = Hispanic origin not stated | 248 (1) |
| FHISP\_R | Father’s Hispanic Origin Recode | 0 = Non-Hispanic  1 = Mexican  2 = Puerto Rican  3 = Cuban  4 = Central and South American  5 = Other and Unknown Hispanic origin  9 = Hispanic origin not stated | 249 (1) |
| MM\_LOPO | Month of Last Other Pregnancy Outcome | -1 = first pregnancy outcome  01-12 = month  99 = unknown | 250-251 (2) |
| YY4\_LOPO | Year of Last Other Pregnancy Outcome | -1 = first pregnancy outcome  (Mother’s yr of birth + 10) through (yr of other pregnancy outcome) = year  9999 = unknown | 252-255 (4) |
| MM\_PDIAB | Pre-pregnancy Diabetes? | 1 = yes  2 = no  9 = unknown  **Note:** This variable is from the "Risk factors in this pregnancy (41)" section of the U.S. standard birth certificate. This variable is coded as “yes" if pre-pregnancy diabetes is coded “Y”, it is coded as “no” if pre-pregnancy diabetes is “N”, else it is coded “unknown”. | 256 (1) |
| MM\_STI | Sexually Transmitted Infection? | 1 = yes  2 = no  9 = unknown  **Note:** This variable is from the "Infections present and/or treated during this pregnancy (42)" section of the U.S. standard birth certificate. This variable is coded as “yes" if any infections are checked, it is coded as “no” if “none of the above” is checked, else it is coded “unknown”. | 257 (1) |
| MMORB | Maternal Morbidity? | 1 = yes  2 = no  9 = unknown  **Note:** This variable is from the "Maternal Morbidity (47)" section of the U.S. standard birth certificate. This variable is coded as “yes" if any complications are checked, it is coded as “no” if “none of the above” is checked, else it is coded “unknown”. | 258 (1) |
| INDUCT | Induction of labor | 1 = yes  2 = no  9 = unknown | 259 (1) |
| BREECH | Breech | 1 = yes  2 = no  9 = unknown | 260 (1) |
| STEROID | Steroids for fetal lung maturation | 1 = yes  2 = no  9 = unknown | 261 (1) |
| EPIDURAL | Epidural or spinal anethesia | 1 = yes  2 = no  9 = unknown | 262 (1) |
| NICU | Admission to NICU | 1 = yes  2 = no  9 = unknown | 263 (1) |

| **Table A2. Variables from the Death Certificate Linked to the Birth Certificate** | | | |
| --- | --- | --- | --- |
| **Variable Name** | **Variable Label** | **Codes** | **Column** |
| BC | Birth Certificate Number | 000000000001 B 999999999999  Right aligned | 1-12 (12) |
| AGED | Age at death in days | 000-365 Number of days | 13-15 (3) |
| MANNER | Manner of death | 1 = Accident  2 = Suicide  3 = Homicide  4 = Pending investigation  5 = Could not determine  6 = Self-inflicted  7 = Natural  Blank = Unknown | 16 (1) |
| UCOD | Underlying cause of death | ICD Code (10th Revision) | 17-20 (4) |
| UCODR130 | 130 infant cause recode | 001-158 Code Range | 21-24 (3) |
| D\_STATE\_O | State of Occurrence | State FIPS | 24-25 (2) |
| D\_COUNTY\_O | County of Occurrence | County FIPS | 26-28 (3) |

**EXHIBIT C**

**FEE SCHEDULE**

**Fees.** Upon signing this agreement(s) MCHB agrees to pay the Jurisdiction VRO the specified funding amount shown below for the Jurisdiction VRO provided as part of the “Special Projects” section of the existing VSCP Contract and any follow-on contract. Additional funding to support monthly linkage for PRAMS oversampling will be provided through a contractor, Abt Associates, as specified in the PRAMS addendum.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | Number of Grants | | | Projected number of annual HS participants | Funding Amount <500=$2,000 500-1,749=$2,500 ≥1,750=$3,000 |
| State | Level 1 | Level 2 | Level 3 |
| AL | 1 | 1 |  | 650 | $2,500 |
| AR | 1 |  |  | 250 | $2,000 |
| AZ | 1 |  | 1 | 750 | $2,500 |
| CA | 2 |  | 2 | 1500 | $2,500 |
| CO | 1 |  |  | 250 | $2,000 |
| CT | 1 | 1 |  | 650 | $2,500 |
| DC |  |  | 1 | 500 | $2,500 |
| FL | 3 | 2 | 1 | 2050 | $3,000 |
| GA | 4 |  |  | 1000 | $2,500 |
| IA |  | 1 |  | 400 | $2,000 |
| IL | 3 | 2 | 1 | 2050 | $3,000 |
| IN | 1 | 1 |  | 650 | $2,500 |
| KS | 2 |  |  | 500 | $2,500 |
| KY |  | 1 |  | 400 | $2,000 |
| LA | 3 |  | 1 | 1250 | $2,500 |
| MA |  |  | 1 | 500 | $2,500 |
| MD |  |  | 1 | 500 | $2,500 |
| MI | 3 | 2 | 1 | 2050 | $3,000 |
| MN | 1 |  |  | 250 | $2,000 |
| MO | 1 | 1 |  | 650 | $2,500 |
| MS | 2 | 1 |  | 900 | $2,500 |
| NC | 2 |  | 1 | 1000 | $2,500 |
| NE | 1 |  |  | 250 | $2,000 |
| NJ | 2 | 1 | 1 | 1400 | $2,500 |
| NM | 2 |  |  | 500 | $2,500 |
| NV | 1 |  |  | 250 | $2,000 |
| NY | 1 | 1 |  | 650 | $2,500 |
| NYC | 3 |  | 2 | 1750 | $3,000 |
| OH | 3 | 1 | 1 | 1650 | $2,500 |
| OK | 3 | 1 |  | 1150 | $2,500 |
| OR | 2 |  |  | 500 | $2,500 |
| PA | 3 | 1 | 2 | 2150 | $3,000 |
| SC |  | 2 |  | 800 | $2,500 |
| SD | 1 |  |  | 250 | $2,000 |
| TN | 1 |  |  | 250 | $2,000 |
| TX | 2 | 1 | 1 | 1400 | $2,500 |
| VA | 1 | 1 |  | 650 | $2,500 |
| WI | 1 |  |  | 250 | $2,000 |
| WV | 1 |  |  | 250 | $2,000 |
|  |  |  |  | Total | $94,500 |

**EXHIBIT D**

**Tentative Data Collection, Transfer, and Linkage Timeline and Instructions**

| **Steps in the Linkage Process** | **Timing** |
| --- | --- |
| NAPHSIS to circulate model data sharing agreement | November 2016 |
| Data sharing and transfer agreement between Vital Records Office (VROs), Healthy Start grantees, PRAMS programs (where applicable), and MCHB/HRSA in place (MCHB/HRSA and partners will facilitate this process) | November 2016 - February 2017 |
| HS grantees collect individual identifiers at enrollment (standard informed consent to be provided) | November 2016 |
| HS grantees selected for PRAMS oversampling begin monthly transfer of individual participant identifiers to VROs (data template and technical assistance will be provided) | March 10th, 2017 – February 10th, 2018 |
| VROs complete monthly linkage for PRAMS batch sampling | March 2017 – February 2018 |
| PRAMS programs include HS participants delivering in CY 2017 in monthly PRAMS batches | April 2017 – March 2018 |
| All HS grantees provide individual participant identifiers to VROs for those with a known or expected delivery in CY 2017 through March 2018 | April 10th, 2018 |
| VROs complete linkage and transfer 2017 linked HS participant birth certificate data + non-participant data in same counties served by HS grantee to MCHB/HRSA (linked data can also be returned to grantee if requested) | May 2018 |
| CDC PRAMS provides MCHB/HRSA with the full PRAMS file of all PRAMS participants in the selected states (both HS participants and non-participants), including linked vital records | September 2018 |
| VROs participating in PRAMS oversampling send any additional requested birth certificate items for PRAMS sample to MCHB/HRSA | September 2018 |
| VROs update linkage of HS participants and non-participant controls to include any subsequent infant death certificates and send data to MCHB/HRSA | May 2019 |
| VROs participating in PRAMS oversampling update linkage of any infant deaths to PRAMS sample and send data to MCHB/HRSA | May 2019 |
| MCHB links data from client-level information (e.g., 3Ps) on service receipt within Healthy Start using the client ID to complete evaluation analyses | May 2018  May 2019 |

**Data Linkage and Transmission Instructions and Schedule.**

Instructions and timing of data transmissions from HS Grantee(s)(s) to Jurisdiction VRO without PRAMS oversample:

* By April 10th 2018, provide participant individual identifiers to state/jurisdiction Vital Records Offices (VROs) for pregnant and postpartum women served with a known or expected delivery date from January 2017 through March of 2018 (format and mode of transmission TBD).

Instructions and timing of data transmissions from Jurisdiction VRO to MCHB (without PRAMS oversample):

1. In April 2018, attempt to link all participants with a known delivery date in 2017 or an expected delivery date through March 2018 (in the event of early delivery) following the general instructions below:
2. Conduct a probabilistic match with available maternal and infant information
3. Only use address, zip code, or county to confirm or narrow matches given that mobility is relatively common in the perinatal period
4. Flag all matched records by appending the HS Client ID number and Date of Enrollment
5. Calculate linkage rates for those with a known delivery date in 2017 (aim of ≥95%) and those with an expected delivery date in 2017 (aim of ≥80%); linkage rates will be monitored by a HRSA contractor who can provide technical assistance where possible
6. Transfer to HRSA any 2017 linked HS participant birth certificate data + non-participant data in same counties served by HS grantee
7. In April 2019, for any State ID#s for 2017 HS participant and non-participant birth certificate data previously transferred to HRSA, transfer any linked infant death certificate data to HRSA; provide overall infant death and birth certificate linkage rates

Instructions and timing of data transmissions from HS Grantee(s) to Jurisdiction VRO with PRAMS oversample:

* Beginning in March 2017 (by the 10th of the month), provide participant individual identifiers to state/jurisdiction VROs ***monthly*** for pregnant and postpartum women served through January of 2017. Subsequent monthly transfers through February 2018, by the 10th of each month, will add any new pregnant or postpartum enrollees in the previous month and/or any updated information for previously submitted participants (format and mode of transmission TBD).
* By April 10th 2018, provide an updated file of participant individual identifiers to state/jurisdiction VROs for pregnant and postpartum women served through March 2018 with a known or expected delivery date in calendar year 2017.

Instructions and timing of data transmissions from Jurisdiction VRO to MCHB (with PRAMS oversample):

1. Beginning in March 2017, attempt to link all participants with a known delivery date through January 2017 or an expected delivery date through April 2017 (in the event of early delivery) following the general instructions below
   1. Conduct a probabilistic match with available maternal and infant information
   2. Only use address, zip code, or county to confirm or narrow matches given that mobility is relatively common in the perinatal period
2. Flag all matched records by appending the HS Client ID number and Date of Enrollment and maintain a database of linked records
3. Calculate linkage rates for those with a known delivery date in January 2017 (aim of ≥95%) and those with an expected delivery date in January 2017 (aim of ≥80%); linkage rates will be monitored by HRSA contractor who can provide technical assistance where possible
4. Include linked HS participants with January 2017 deliveries in the January 2017 batch for PRAMS sampling, which is drawn in April (include a State ID# to which any subsequent infant deaths can be linked)
5. In April 2017 and each subsequent month through February 2018, identify any new or previously unlinked participants transferred from HS grantee by cross-referencing any previously linked HS client IDs in linked database; repeat steps 1-4
6. In September 2018, for any State ID#s of 2017 births sampled in PRAMS, transfer additional HRSA-requested birth certificate items beyond standard PRAMS file
7. In April 2019, for any State ID#s for 2017 HS participant and non-participant birth certificate data previously transferred to HRSA, transfer any linked infant death certificate data to HRSA; provide overall infant death and birth certificate linkage rates
8. In April 2019, for any State ID#s of 2017 births sampled in PRAMS, transfer any linked infant death certificate data to HRSA

Instructions and timing of data transmissions from PRAMS to MCHB via CDC PRAMS:

1. Beginning with April 2017 batch (primarily January 2017 births), include identified HS participants in the PRAMS sample and contact HS participants for survey administration in monthly batches through February 2018 (identified by HS client-ID and enrollment date; these two variables plus a state ID # will be the only additions to the PRAMS contact file and standard vital records file within PIDS)
2. Track response rates for HS participants versus non-participants by batch; response rates will be monitored by HRSA contractor who can provide technical assistance where possible
3. CDC PRAMS provides MCHB/HRSA with the full PRAMS file of all PRAMS participants in the selected states (both HS participants and non-participants), including linked vital records for analytic purposes (maintain HS client-id and Enrollment date to identify HS participants)

Addendum to

Data Use and Non-Disclosure Agreement

Between

[Vital Records Office, Jurisdiction Health Agency]

and

[Healthy Start Grantee(s)]

and

Maternal and Child Health Bureau, Health Resources and Services Administration

for

[Jurisdiction Pregnancy Risk Assessment Monitoring System (PRAMS) Program]

This Addendum to the data use and non-disclosure agreement (“Agreement”) is established for the purpose of incorporating the data shared for the PRAMS oversample component of the Healthy Start evaluation into the original Data Use and Non-Disclosure Agreement.

By signing the Addendum each signatory agrees to abide by the provisions of the original Data Use Agreement and Non-Disclosure Agreement (attached) as well as any additional requirements specified in this Addendum. This Addendum is between the [Vital Records Office, Jurisdiction Health Agency] (“Jurisdiction VRO”), [Healthy Start Grantee(s)] (“HS Grantee(s)”), the Maternal and Child Health Bureau of the Health Resources and Services Administration (“MCHB”), and the [Jurisdiction PRAMS Program] (“PRAMS Program”) for the purposes described below. HS Grantee(s), MCHB, PRAMS Program, and the Jurisdiction VRO may be individually referred to herein as “Party” or collectively as “Parties.”

The Jurisdiction VRO collects, owns and maintains certain birth and death records and related data elements for births and linked infant deaths occurring within the Jurisdiction VRO’s geographic jurisdiction, and provides, under separate agreement, selected data from those vital records to the PRAMS Program to supplement the data collected from mothers of newborns by the PRAMS Program.

As part of the national Healthy Start evaluation the PRAMS program will oversample Healthy Start participants who have consented to participate in the national Healthy Start evaluation. To accomplish this activity, the HS Grantee will provide to the Jurisdiction on a monthly basis identifying information for all consenting HS participants. The VRO will link that information to vital records data and share the resulting data set to the PRAMS Program, so that the consenting HS participants can be included in the PRAMS oversample. The consolidated Healthy Start, Jurisdiction VRO, and PRAMS data obtained will then be transmitted by the PRAMS Program to CDC’s national PRAMS program for incorporation into the national Healthy Start evaluation conducted by MCHB. The instructions and timeline for these activities are set forth in Exhibit D of the main agreement. Payment provisions and tasks for responsible parties are established in Exhibit A of this addendum.

**Permitted Uses of Data.**

**a.** MCHB may use the vital records data provided by PRAMS solely for the purpose of conducting the national Healthy Start evaluation.

**b.** Any other use of or access to the PRAMS Data by MCHB or any other Authorized User will require prior written authorization by the PRAMS program.

**Publication.** PRAMS programs require acknowledgment of the Data they provided to MCHB in any publication, report, poster, talk, news release, web page, or other presentation or use (print, or electronic) developed from the Data or describing the Project or results of the Project by MCHB, its staff, contractors, or other Authorized Users of the Data.

The undersigned warrant that they are authorized representatives of their respective Party and that they have full power and authority to enter into this Agreement and bind their respective Party to its terms and, in the case of a Jurisdiction VRO, to its applicable State terms.

[HS Grantee]:

By:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Name:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Title:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Date:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

[Jurisdiction VRO]:

By:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Name:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Title:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Date:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

[MCHB]:

By:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Name:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Title:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Date:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

[PRAMS Program:

By:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Name:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Title:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Date:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Exhibit A

Payment Provisions and Tasks for PRAMS Oversample Activities

Upon signing of this agreement, the following parties shall receive the following funding amounts through an evaluation contractor, Abt Associates, to support the tasks listed.

HS Grantee: $1,500 to support outreach, materials, and training to promote HS participant response rates to PRAMS

Vital Records Offices: $6,000 per HS grantee participating in the PRAMS oversample to support monthly data linkage and initial alteration and testing of the PRAMS sampling program/algorithm to include HS participants

PRAMS Programs: $100 per expected HS participant birth to support staff time for the additional interviews, survey printing, incentives, supplies, mailings, and data entry required by the oversampling (expected HS participant births are 250 for Level 1 grantees, 400 for Level 2 grantees, 500 for Level 3 grantees)