**Form Approved**

**OMB No. 0920-0879**

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**Birth Certificate and Hospital Discharge Linkage—State Survey**

Thank you for your agreement to participate in this survey.

Please note that due to software requirements, the survey must be completed and submitted online in one session. If you are not ready to complete the entire survey, please wait until you have all your responses prepared before you begin.

If you have any questions, please contact [NAME] at [Email].

As was noted in the email you received, the purpose of this survey is to understand the status of birth certificate and hospital discharge linkages in the United States and to improve surveillance, research policy, and programs around maternal, infant, and child health.

The data collected from this survey will be used to understand whether a state has a birth certificate and hospital discharge linkage, the process and quality of the linkage, the resources related to linking, and barriers and limitations to linkages.

Your feedback will also be used for improvements in data linkages that inform public health surveillance, research, policy, and programs around pregnancy conditions, risk behaviors, and neonatal outcomes.

The survey is being conducted through collaboration with AMCHP, NAPHSIS, and the Centers for Disease Control and Prevention.

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| 1. Has any organization, including your state health department, or another organization or university, linked your state’s birth records and hospital discharge records (maternal and/or infant discharges) in the last 4 years? | \_\_\_ Yes  \_\_\_ No  \_\_Don’t know | If no or don’t know, go to question 22 |
| 1. Which inpatient hospital discharge records are linked to the birth record, in the last 4 years? | \_\_Maternal  \_\_Infant  \_\_Both |  |
| 1. Does your state health department currently have access to this linked file for analysis? | \_\_\_ Yes  \_\_\_ No  \_\_Don’t know |  |
| 1. How often is the linked file updated? | \_\_Less than once every two years  \_\_Every other year  \_\_Annually  \_\_More frequently than annually  \_\_  \_\_Have only done the linkage once  \_\_Other (specify)  \_\_Don’t know |  |
| 1. Is your linkage automated (i.e. when data are received, there is already code developed to clean and merge into full dataset)? | \_\_Yes  \_\_No  \_\_Don’t know | If no, go to question 7  If don’t know, go to question 9 |
| 1. If yes, what percentage of records can be linked electronically without manual judgment or intervention? | About\_\_\_\_% | Go to question 8 |
| 1. If no, why not? | \_\_Lack of experience  \_\_Lack of software  \_\_Data not provided in an electronic format  \_\_Data files are sent in different format  \_\_Other (specify)  \_\_Don’t know |  |
| 1. What data software is used to automate the linkage? | --By Hand  --SAS  --Stata  --SPSS  --Microsoft Access  --SQL Server  --Oracle  --Fril  --LinkPlus  --Link Pro  --Link King  --Other (specify) |  |
| 1. Would you be interested in collaborating with other states in sharing linkage processes, including lessons learned, challenges encountered, and codes? | \_\_Yes  \_\_No  Not Sure | If yes, go to question 12  (if no, proceed to Q10)  If not sure, go to question 11 |
| 1. If no, why not? (check all that apply) | \_\_Lack of staff time  \_\_Confidentiality of data  \_\_Other (specify) | Go to question 12 |
| 1. If not sure, what are your concerns? (check all that apply) | \_\_Time commitment  \_\_Cost  \_\_Confidentiality of data  \_\_Other (specify) | Go to question 12 |
| 1. You stated that an organization conducts a linkage in your state, more specifically, has your **state health department** conducted this linkage, either maternal or infant, in the last 4 years? | \_\_\_ Yes  \_\_\_ No  \_\_Don’t know | If no or don’t know, go to question 14 |
| 1. Which organizational unit or program in the state health department was responsible for doing the linkage? (Check all that apply) | \_\_Vital Records/Health Statistics Office  \_\_Epidemiology Office  \_\_MCH Program Office  \_\_Office responsible for collecting hospital discharge abstracts  \_\_Other (specify) |  |
| 1. What data elements are used to link the data sources? (Check all that apply) | \_\_Maternal social security number  \_\_Child’s Date of birth  \_\_Child’s name  \_\_Race  \_\_Gender of child  \_\_Mother’s first name  \_\_Mother’s last name  \_\_Mother’s surname prior to first marriage  \_\_Hospital medical record  \_\_Birth Facility/Hospital Name  \_\_Discharge Date  \_\_Patient Address (City, state, house number, zip code)  \_\_Other patient identifier (specify)  \_\_Other (specify)  \_\_Don’t know |  |
| 1. What is the methodology used for linking the records? (Check all that apply) | \_\_Deterministic (specify %)  \_\_Probabalistic (specify %)  \_\_Other (specify and %) |  |
| 1. Has the quality of the birth-hospital record linkage been evaluated? | \_\_\_ Yes  \_\_\_ No  \_\_Don’t know | If no or don’t know, go to question 18 |
| 1. How has the quality of the linkage been evaluated? (Check all that apply) | \_\_Review sample of records  \_\_Chart review  \_\_Other (specify) |  |
| 1. Does your state utilize the linked birth and hospital record dataset for research, policy, surveillance or programs? | \_\_Yes  \_\_No  \_\_Don’t know | If no or don’t know, go to question 20 |
| 1. If yes, how does your state **currently use** your birth-hospital record linked dataset? (Check all that apply) | \_\_Statistical reports (regular published or unpublished written reports)  \_\_ Surveillance (understand trends and prevalence estimates)  \_\_ Special studies  \_\_ Policy evaluation (pass legislation, provide legal support)  \_\_Program or quality improvement  \_\_Other (specify) |  |
| 1. What other ways **would you like to use** your birth-hospital record linked dataset? (Check all that apply) | \_\_Statistical reports (regular published or unpublished written reports)  \_\_ Surveillance (understand trends and prevalence estimates)  \_\_ Special studies  \_\_ Policy evaluation (pass legislation, provide legal support)  \_\_Program or quality improvement  \_\_Other (specify) |  |
| 1. What prevents your states from using the birth-hospital record linked dataset the way you would like to use it? | \_\_ Cost  \_\_ Lack of staff time available  \_\_\_Lack of interest in utilizing the linkage  \_\_Most people are not aware of the availability of linkage  \_\_Access to linkage too difficult to obtain  \_\_ Other (specify)  \_\_Don’t know | Skip to Q25 |
| 1. In your organization or state, what prevents birth-hospital discharge linkages from occuring? (check all that apply) | \_\_ Cost  \_\_ Lack of staff time available for linkage  \_\_Data linkage is not a priority  \_\_Cannot access raw hospital discharge data  \_\_Cannot access raw birth certificate data  \_\_No statewide hospital discharge data collected  \_\_\_Linkage fields (e.g. name, SSN, or other identifiers) not collected or not available  \_\_\_Lack of effective matching/linkage software  \_\_\_Lack of interest in obtaining/using these data  \_\_ Other (specify)  \_\_Don’t know |  |
| 1. Does your organization or state want to have a linkage of birth and hospital discharge records? | \_\_Yes, definitely  \_\_Yes, no rush  \_\_Undetermined  \_\_No, not right now  \_\_No, never  \_\_Don’t know |  |
| 1. Would you be interested in collaborating with other states to learn about the linkage process? | \_\_Yes  \_\_No  \_\_Don’t know |  |
| The following questions are to get an understanding of the quality of each individual data source. Please answer to the best of your ability. |  |  |
| 1. Has the quality of the data items from the birth record **only** been evaluated? | \_\_\_ Yes  \_\_\_ No  \_\_Don’t know | If no or don’t know, go to question 27 |
| 1. How has the quality of the data items from the birth record been evaluated? (Check all that apply) | \_\_ Medical chart validation  \_\_Linkage with other data sets  \_\_Other (specify)  \_\_Don’t know |  |
| 1. Has the quality of the data items from the hospital discharge abstract **only**  been evaluated? | \_\_\_ Yes  \_\_\_ No  \_\_Don’t know | If no or don’t know, go to question 29 |
| 1. How has the quality of the data items from the hospital discharge abstract been evaluated? (Check all that apply) | \_\_ Medical chart validation  \_\_Linkage with other data sets  \_\_Other (specify)  \_\_Don’t know |  |
| 1. Is there a state developed instruction manual for completing the birth record for the birth clerk? | \_\_Yes  \_\_No  \_\_Don’t know |  |
| 1. Are there training programs available for hospital and birthing center staff on how to fill out the birth record? | \_\_Yes  \_\_No  \_\_Don’t know | If no or don’t know, go to question 32 |
| 1. If yes, who provides the trainings on procedures for completing the birth record? | \_\_Online (if online, offered by whom?)  \_\_Someone in the health department (specify)  \_\_Someone from a hospital (specify  \_\_Other (specify)  \_\_Don’t know |  |
| 1. Are personnel completing the birth record provided any guidance (written, training, consultation) on how to prioritize different sources of information and make decisions when there are conflicting values? | \_\_Yes  \_\_No  \_\_Don’t know | If no or don’t know, go to question 34 |
| 1. How often is training to complete the birth record offered? | \_\_Monthly  \_\_Quarterly  \_\_Annually  \_\_Less frequently than once a year  \_\_As needed or on demand  \_\_Available online at anytime  \_\_Other (specify)  \_\_Don’t know |  |
| 1. Is there an instruction manual for abstracting hospital discharge data? | \_\_Yes  \_\_No  \_\_Don’t know |  |
| 1. Are there training programs available for hospital and birthing center staff on how to abstract data from hospital discharge data records? | \_\_Yes  \_\_No  \_\_Don’t know | If no or don’t know, go to question 37 |
| 1. If yes, who provides the trainings on procedures for abstracting the hospital discharge data? | \_\_Online (if online, who is offering the training)  \_\_Hospital Association  \_\_Someone in the health department (specify)  \_\_Someone from a hospital (specify  \_\_Other (specify)  \_\_Don’t know |  |
| 1. Are personnel abstracting data from discharge records given guidance on how to prioritize different sources of information and make decisions when there are conflicting values? | \_\_Yes  \_\_No  \_\_Don’t know | If no or don’t know, go to 39 |
| 1. How often is training to abstract hospital discharge records offered? | \_\_Monthly  \_\_Quarterly  \_\_Annually  \_\_Less frequently than once a year  \_\_As needed or on demand  \_\_Available online at anytime  \_\_Other (specify) | Go to 39 |
| 1. What other data do you link to the birth record? (Check all that apply) | \_\_No other linkages  \_\_WIC  \_\_Medicaid  \_\_Infant deaths  \_\_Death certificate of women of reproductive age  \_\_PRAMS  \_\_Birth defects registry  \_\_Newborn blood spot screening  \_\_Newborn hearing screening  \_\_Immunizations  \_\_Family planning (Title X)  \_\_Health department client data  \_\_Public health program data (Healthy Start, home visiting, etc.)  \_\_Education data  \_\_Child maltreatment data  \_\_Children’s special healthcare program  \_\_Health insurance other than Medicaid  \_\_Outpatient Records  \_\_ER/Ambulatory Data  \_\_EMS Registry  \_\_Other (specify) |  |
| 1. Is there any other information you think we should know regarding hospital discharge and birth record linkages? |  |  |
| 1. Please state your jurisdiction and any additional comments on this survey? |  |  |