Birth Certificate and Hospital Discharge Linkage—State Survey

OSTLTS Generic Information Collection Request
OMB No. 0920-0879

Supporting Statement – Section A

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Section A – Justification

1. Circumstances Making the Collection of Information Necessary

Background

This data collection is being conducted using the Generic Information Collection mechanism of the OSTLTS Survey Center (OSC) – OMB No. 0920-0879. The respondent universe for this data collection aligns with that of the OSC. Information will be collected about perceptions of data linkages and knowledge of how linkages are conducted and utilized within state health departments and their external partners. Respondents will be state vital records registrars and State Systems Development Initiative (SSDI) Coordinators acting in their official capacities. SSDI coordinators work with the state maternal and child health program to help build infrastructure that result in comprehensive, community-based systems of care for all children and their families. The National Association for Public Health Statistics and Information System (NAPHSIS) will administer the survey to vital statistics registrars, and the Association of Maternal and Child Health Programs (AMCHP) will administer the survey to SSDI coordinators. Because birth certificate and hospital discharge data are not always linked solely by the vital registrars and often times are managed by maternal and child health programs it is necessary to collect information from both types of respondents.

Neither birth certificate nor administrative hospital discharge data alone are sufficient to address surveillance of pregnancy conditions, risk behavior, and neonatal outcomes. Birth certificate data lacks detailed and accurate maternal and pregnancy-related complications data, while hospital discharge information lacks information about gestational age, socioeconomic status, and other variables such as body mass index, gestational weight gain, and maternal smoking. Linking together birth certificate and hospital discharge data combines information in order to provide a more comprehensive data system regarding sociodemographic characteristics, prenatal care, and maternal morbidity information. Detailed health outcome and resource utilization data can be used jointly for surveillance and other epidemiological analyses. States use linked data to inform maternal and child health programs, improve public health policy, and as a data source for monitoring state and national trends of pregnancy conditions, risk behaviors, and neonatal outcomes. Linked data also provides the most feasible source for examining and addressing contributions of pregnancy complications to known modifiable risk factors within the public and private prenatal health care setting.

Studies that have previously examined the accuracy of the variables in the data sources contained in the 1989 version of the birth certificate and hospital discharge summary have shown that: (1) medical conditions and pregnancy complications are grossly underreported on birth certificates; (2) hospital discharge data provides a fairly accurate report of health outcomes during pregnancy, and (3) reporting of medical conditions and pregnancy complications in the linked birth certificate and hospital discharge data files is superior in comparison with data from either of the two sources alone (1-3). Moreover, since the 2003 revised birth certificate has been implemented, only a few studies have reported data using linked 2003 birth certificate with

hospital discharge data (4). Therefore, to date it is not clear how many states conduct these linkages, the quality of these linkages, and the limitations to conducting these linkages. This evaluation will help inform us regarding the need to develop more systematized linkage system, the resources needed to create or expand current linkages, and the capacity and interests states have to maintain such linkages.

The purpose of this project is to administer a short data collection to 52 vital records jurisdictions which includes the 50 states, Washington DC, and New York City, 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 following objectives will be answered through this data collection:

1. Determine how many jurisdictions currently link birth certificate and hospital discharge data.
2. Identify the process the jurisdictions use to do the linkage (probabilistic vs. deterministic), quality assessment measures taken, and resources needed (cost, time, materials).
3. Describe barriers to linkage and limitations jurisdictions have in conducting linkages.
4. Determine the interest states have in creating, maintaining, and utilizing such a linkage.

This data collection is authorized by Section 301 of the Public Health Service Act (42 U.S.C. 241).

Privacy Impact Assessment

Overview of the Data Collection System – This is a one-time data collection co-sponsored by CDC and two national organizations that have special, direct relationships with state vital records registrars and SSDI coordinators. Information regarding whether or not the states conduct linkage of birth certificate and hospital discharge data, the process for linkage, resources required for linkage, and barriers/limitations to linking will be collected through a web-based questionnaire **(Attachment A)** made available to respondents by one of the co-sponsoring organizations. The National Association for Public Health Statistics and Information System (NAPHSIS) will administer the data collection to vital statistics registrars (see **Attachment B**), and the Association of Maternal and Child Health Programs (AMCHP) will administer the data collection instrument to SSDI coordinators (see **Attachment C**). One vital registrar or director of health statistics and one SSDI coordinator will be surveyed in each state or jurisdiction.
The length of the project will be one year.

Items of Information to be Collected –

The data collection instrument consists of 41 questions of various types including dichotomous, multiple response, filter, and open ended response formats. An effort was made to limit questions requiring narrative response from the respondents (maximum of two in the entire survey). The survey will collect information on the following:

a. Whether or not a linkage exists within the state
b. Whether or not the respondent has access to the linkage in the state

c. Linkage process including where the linkage occurs, identifiers used to conduct the linkage, quality of the linkage, quality of the data items from the data sources, frequency of the linkage
d. Resources related to the linkage including annual FTE required to maintain linkage, whether the linkages are automated, and the software used to conduct linkages
e. Linkage utilization for research, policy, or programs
f. Barriers and limitations to linkages
g. Willingness to collaborate on sharing linkage processes, lessons learned, and codes

Responses are identifiable but institutional in nature rather than personal. Vital registrars and SSDI coordinators may need to consult with other department staff in order to accurately respond to survey questions. To facilitate efficient use of their time, respondents will be sent an electronic copy of the survey along with the link to the web-based version. Respondents may use the electronic copy to solicit needed information from appropriate staff. Respondents can then access the web-based version and complete the survey.

Identification of Website(s) and Website Content Directed at Children Under 13 Years of Age – The data collection system involves using a web-based survey. Respondents will be sent a link directing them to the online survey only (i.e., not a website). No website content will be directed at children.

2. Purpose and Use of the Information Collection

The information collected 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. Information derived from the survey will help inform both the CDC and the states. Importantly, it will be used to assess the feasibility of creating standardized linkages across states, highlight the programmatic needs so that CDC can provide appropriate technical assistance and resources to conduct linkages, and be used as a benchmark to inform decisions about future linkages. In addition, the results of the survey will also be disseminated to health officials to share information about linkages in different states and how it can be used to inform public health surveillance, research, policy, and programs around pregnancy conditions, risk behaviors, and neonatal outcomes. Without collecting this information, it would be difficult to judge the value of linkages and determine whether or not future investment in linkages is warranted.

Privacy Impact Assessment

The information is being collected to determine 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. The survey will assess vital registrar and SSDI coordinators perceptions of data linkages and knowledge of how the linkages are conducted and utilized within the department of health. The data and information collected will be used to assess the value of linkages and improve future linkages.

No sensitive information is being collected. No individually identifiable information is being collected. The proposed data collection will have little or no effect on respondent privacy. Respondents are participating in their official capacity as health officials in state (or District) departments of health, and therefore we will only have information on the state they are from and not any other individual information. The national organizations collecting the data will know who the survey was delivered to in order to follow up with them if necessary.

3. Use of Improved Information Technology and Burden Reduction

Data will be collected via a web-based questionnaire allowing respondents to complete and submit their responses electronically in Zoomerang. This method was chosen to reduce the overall burden on respondents. The survey was designed to collect the minimum information necessary for the purposes of this project (i.e., limited to 41 survey questions). Example screen shots of the web survey instrument can be found in **Appendix B and Appendix C**.

4. Efforts to Identify Duplication and Use of Similar Information

To our knowledge, this information being collected has not been collected in the past. Currently, there is a funding opportunity announcement (FOA) validating the quality of variables found in already established linkages. However, this FOA will not have any information that will be collected in this survey. In addition, we have reviewed the literature to ensure that there are no duplicative surveys being conducted or have been conducted in the past. In addition, there are no other data sources where this information can be collected and can substitute for survey responses.

5. Impact on Small Businesses or Other Small Entities

No small businesses will be involved in this data collection.

6. Consequences of Collecting the Information Less Frequently

The purpose of CDC's request for this generic clearance is to ensure collection of data that is not otherwise available. Specifically, without this data there would be:

- No systematically obtained information to support judgments about the value and utility of linking administrative data, in particular birth certificate and hospital discharge data in helping to advance evidence-based public health policy and practice.
- No information for decision-making about the potential future development of data linkages used for surveillance, research, policy, and program purposes.

This request is for a one time data collection. There are no legal obstacles to reduce the burden.

7. Special Circumstances Relating to the Guidelines of 5 CFR 1320.5

There are no special circumstances with this information collection package. This request fully complies with the regulation 5 CFR 1320.5 and will be voluntary.

8. Comments in Response to the Federal Register Notice and Efforts to Consult Outside the Agency

This data collection is being conducted using the Generic Information Collection mechanism of the OSTLTS Survey Center (OSC) – OMB No. 0920-0879. A 60-day Federal Register Notice was published in the Federal Register on October 22, 2010, Vol. 75, No. 204; pp. 65353-54. Two comments were received from the Association of State and Territorial Health Officials (ASTHO), and the National Association of County and City Health Officials (NACCHO).

CDC partners with professional STLT organizations, such as the Association of State and Territorial Health Officials (ASTHO), the National Association of County and City Health Officials (NACCHO), and the National Association of Local Boards of Health (NALBOH) along with the National Center for Health Statistics (NCHS) to ensure that the collection requests under individual ICs are not in conflict with collections they have or will have in the field within the same timeframe.

9. Explanation of Any Payment or Gift to Respondents

CDC will not provide payments or gifts to respondents.

10. Assurance of Confidentiality Provided to Respondents

The Privacy Act does not apply to this data collection. Employees of state and local public health agencies will be speaking from their official roles and will not be asked, nor will they provide individually identifiable information.

This data collection is not research involving human subjects.

11. Justification for Sensitive Questions

No information will be collected that are of personal or sensitive nature.

12. Estimates of Annualized Burden Hours and Costs

The estimate for burden hours is based on a pilot test of the survey instrument by nine public health professionals. In the pilot test, the average time to complete the survey including time for reviewing instructions, gathering needed information and completing the survey, was approximately 20 minutes. Based on these results, the estimated time range for actual respondents to complete the survey is 20-25 minutes. For the purposes of estimating burden hours, the upper limit of this range (i.e., 25 minutes) is used.

Estimates for the average hourly wage for respondents are based on the Department of Labor (DOL) National Compensation Survey estimate for management occupations – medical and health services managers in state government (http://www.bls.gov/ncs/ocs/sp/nctb1349.pdf). Based on DOL data, an average hourly wage of $57.11 is estimated for all 104 respondents. Table A-12 shows estimated burden and cost information.

Table A-12: Estimated Annualized Burden Hours and Costs to Respondents – Linkage State Survey

Type of Respondent	Form Name	No. of Respondents	No. of Responses per Respondent	Average Burden per Response (in hours)	Total Burden Hours	Hourly Wage Rate	Total Respondent Costs
Vital Registrars	Birth Certificate and Hospital Discharge Linkage—State Survey (NAPHSIS)	52	1	25/60	22	$57.11	$1,256
SSDI Coordinators	Birth Certificate and Hospital Discharge Linkage—State Survey (AMCHP)	52	1	25/60	22	$57.11	$1256
TOTALS		**104**	**2**		**44**		**$2,512**

13. Estimates of Other Total Annual Cost Burden to Respondents or Record Keepers

There will be no direct costs to the respondents other than their time to participate in each survey.

14. Annualized Cost to the Government

There are no equipment or overhead costs. The cost to the federal government would be the salary of CDC staff supporting the data collection activities and associated tasks, and salary and activities for the two national organizations.

The lead staff for this project is an Epidemiologist. The development of the survey instrument included the assistance of a senior epidemiologist and the two national organizations. The two national organizations will identify the universe of survey respondents, design the questionnaire into Zoomerang, collect the data; code, enter, and prepare the data for analysis; and conduct preliminary data analyses with ongoing consultation provided by the CDC. Hourly rates of $47.80 for GS-13 (step 6) who is putting in 10% of time, and $56.48 for GS-14 (step 6) who is putting in 5% of time were used to estimate staff costs. The estimated cost to the federal government is $64,962.35. Table A-14 describes how this cost estimate was calculated.

Table A-14: Estimated Annualized Cost to the Federal Government

Staff (FTE)	Average Hours per Collection (or % effort)	Average Hourly Rate	Average Cost
Epidemiologist (GS-13) Instrument development, OMB package preparation, data collection, data coding and entry, quality control, data analysis, report preparation	10%	$47.80	$9,975
Senior Epidemiologist (GS-14) Review and consultation for instrument development, OMB package preparation, data collection, data analysis, report preparation	5%	$56.48	$4,987
NAPHSIS Instrument development, pilot testing, web-based survey programming, data collection, data coding and entry, quality control, data analysis, report preparation	2-3 individuals		$30,000
AMCHP Instrument development, pilot testing, web-based survey programming, data collection, data coding and entry, quality control, data analysis, report preparation	2 individuals		$20,000
Estimated Total Cost of Information Collection			**$ 64,962**

15. Explanation for Program Changes or Adjustments

This is a new, one-time data collection.

16. Plans for Tabulation and Publication and Project Time Schedule

The results will be used to understand the needs of data linkage technical assistance within states, a summary report will be shared with the states, and a manuscript will be written for peer-review publication.

Project Time Schedule

- ❑ Design survey questionnaire.....(COMPLETE)
- ❑ Pilot test survey questionnaire.....(COMPLETE)
- ❑ Enter survey into Zoomerang.....(COMPLETE)
- ❑ Prepare OMB package.....(COMPLETE)
- ❑ Submit OMB package.....(Aug 2012)
- ❑ OMB approval.....(TBD)
- ❑ Conduct survey.....(Survey open 6 weeks after OMB approval)
- ❑ Collect, code, enter, quality control, and analyze data.....(12 weeks)
- ❑ Prepare report.....(8 weeks)
- ❑ Disseminate results/reports.....(8 weeks)

17. Reason(s) Display of OMB Expiration Date is Inappropriate

The OMB expiration date will be displayed. No exemption is requested.

18. Exceptions to Certification for Paperwork Reduction Act Submissions

There are no exceptions to the certification. These activities comply with the requirements in 5 CFR 1320.9.

References:

(1) Lydon-Rochelle MT., Holt VL., Cardenas V., Nelson JC., Easterling TR., Gardella C., Callaghan WM. The Reporting of pre-existing maternal medical conditions and complications of pregnancy on birth certificates and hospital discharge data. American Journal of Obstetrics and Gynecology. 2005; 193:125-34.

(2) Ananth C.V. Perinatal epidemiologic research with vital statistics data: Validity is the essential. American Journal of Obestrics and Gynecology. 2005; 193: 5-6.

(3) Devlin H.M., Desai J, Walasazek A. Reviewing Performance of Birth Certificate and Hospital Discharge Data to Identify Births Complicated by Maternal Diabetes. 2009; 13:660-666.

(4) Kim SY, England L, Sappenfield W, Wilson HG, Bish CL, Salihu HM, Sharma AJ. Racial/Ethnic differences in the percentage of gestational diabetes mellitus cases attributable to overweight and obesity, Florida, 2004-2007. *Prev Chronic Dis* 2012 Apr;9:E88.

LIST OF ATTACHMENTS – Section A

Note: Attachments are included as separate files as instructed.

A. Data Collection Questions—Word Document

B. NAPHSIS Screen Shots

C. AMCHP Screen Shots