

Public Health Service Centers for Disease Control and Prevention

National Center for Health Statistics 6525 Belcrest Road, Room 820 Hyattsville, Maryland 20782-2003

August 29, 2001

Dear Colleague:

I want to thank you and your staffs for the very helpful and thoughtful comments we received on the specifications for collecting and reporting the items on the revised birth certificate. This letter includes responses on a number of issues that were raised by individual States which we thought were of general interest. We hope to have the birth specifications on our web site within the month. I anticipate writing you again soon with additional information concerning the electronic systems and specifications for the race items as well as other topics needing further clarification.

<u>Justification for inclusion or exclusion of items on the revised birth certificate</u> Many comments related directly to decisions made by the Panel to Evaluate the U.S. Standard Certificates and Reports (The Panel). Commenters asked for justifications for the inclusion of certain items on the standard certificates and recommended changes to the wording of items,

As you know, the standard certificates and worksheets represent a model developed by a panel of 11 State representatives and a number of nationally recognized medical and health experts. The Panel's goal was to maintain the certificate's fundamental legal function while developing a high quality national birth data file. The Panel considered not only whether a specific item should be included on the standard, but also labored to develop the best wording for each item. Their decisions were based not only on their own wide expertise, but included consultation with subject-matter experts (a separate panel of perinatologists was convened to advise on the medical/health items), and a thorough review of precedent items (e.g., the revised question on tobacco use was tested successfully in California.). Items were included on the revised Standard only if they were deemed necessary for legal, research, statistical, or public health programs, and were considered to be collectable with reasonable completeness and accuracy. Detailed information on the Panel's mission and explanations for inclusion/exclusion of specific items are found in "The Report of the Panel to Evaluate the U.S. Standard Certificates and Reports" which will soon be available on our web site.

The Panel also recommended that items and the worksheets be carefully tested before implementation, and substantial effort was devoted to testing all individual items and both worksheets. The testing took into account the clarity of item wording, the sensitivity of questions for the mother, the availability/accessability of items in the medical records taking into consideration the likelihood that these staff may not have clinical training, and the overall burden the worksheet presented to hospital staff.

## Is it "mandatory" to collect all items on the Standard?

We were asked if it is "mandatory" that States collect particular items. NCHS strongly encourages the States to conform to the standards as closely as possible. Even small deviations from the Standard can have critical implications for both the State and national files because of the loss of data quality and comparability. States may assume that all non-legal items will be included in the NCHS minimum data set.

## Can categories be added to the Standard?

In general, additional categories for items are acceptable, so long as they are appended to the end of the standard list, and data transmitted to NCHS are reported in the standard categories. We will ask to review additions to gauge the potential impact. For example, a substantially longer list of congenital anomalies could compromise collection of the anomalies recommended for the standard certificate. The document "Specifications for Collecting and Editing..." in the specifications packet includes a discussion of this topic. This document is also available on our web site.

## The potential additional time burden on hospital staff of the medical/health items

Concerns were also raised regarding the additional burden imposed by the increased number of items included on the revised certificate. As mentioned above, the facility worksheet (FWS) has been tested by NCHS and by several States. The NCHS testing was performed in hospitals with hospital staff who normally gather birth certificate information. We found that staff generally reacted favorably to the worksheet and that the time burden imposed by the worksheet was not substantially greater than that of the current certificate. The time taken to complete the worksheet will also undoubtably decline as staff gain familiarity with it.

To further improve on the efficiency of the facility worksheet (FWS) we plan to have its format professionally evaluated. We are also nearing completion of a comprehensive instruction manual for use with the FWS. This manual will be available both in hard copy and electronically (preferably with hot links to the EBC). The instructions are designed to help staff abstract information from the medical records. It includes detailed recommendations for specific sources and keywords and common abbreviations for medical terms.

## Is there flexibility in design of State EBCs?

There was little national guidance on the design of electronic systems when EBCs were first developed in the late 1980's and early 1990's. This oversight contributed to the lack of standardization among reporting areas and pervasive data quality issues which continue to this day. (See "The Report of the Working Group.") Both national and State vital statistics data sets are

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routinely, and often justifiably, criticized for questionable data quality. To improve data quality, the Panel recommended that NCHS develop detailed specifications and guidelines for electronic systems.

To enhance standardization and comparability of data across the country and ensure high quality data, it is imperative that the States follow the specifications closely. While some flexibility in design is necessary, there are general components of the systems which we believe are essential for all areas to adopt. We will continue to work with the software vendors and the individual States to promote understanding of the guidelines. Please see the overview entitled "Specifications for collecting and editing the United States standard certificates of birth and death" which was included in the draft birth specifications packet and is available on our web site. You will receive a letter summarizing our guidelines for electronic systems soon.

## How will the new software be reviewed?

NCHS is developing methods to evaluate State software at the earliest possible stages of the process. We strongly recommend that all State software be evaluated with the NCHS prior to implementation and will offer assistance to the States and the vendors to ensure that systems are tested sufficiently. We will provide more detail on software testing in the upcoming letter on the electronic systems.

It is not feasible for NCHS to review all version changes to software. However, we do recommend that systems include methods to track versions and inform NCHS when a version change has occurred. This notice should greatly improve our ability to identify and fix data problems.

#### Information on the electronic screens

The recommended electronic screens were designed with the minimum amount of messages/information we believe is necessary to ensure that the individual entering the data has all the information they need to do so accurately. A well-designed electronic system can incorporate this information so that it is helpful, not burdensome, to hospital staff. A well-designed system should also lessen or eliminate the need for "beginner" and "advanced" levels.

# Order and wording differences between the birth certificate, the worksheets and the specifications

While it was necessary to restrict the hard-copy birth certificate to a limited 2-page format, no such restrictions in format were necessary for the worksheets. To improve data gathering, and make these instruments as efficient as possible for mothers and hospital staff to complete, the mother's worksheet was designed to flow logically and easily for the mother, and the facility worksheet was were designed to flow closely with medical records. We strongly encourage the use of the worksheets for data collection for all venues.

There are also some wording differences between the certificate and worksheets. Again this is intentional and is meant to take advantage of the more flexible format of the worksheet to

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improve on item wording and instructions. As a result, there are some differences in wording, but not meaning, between the two documents.

The electronic systems generally should follow the flow of the worksheet, that is items and categories are in the same order. The specifications for the electronic systems were written with that intent. We are reviewing the draft specifications carefully to ensure that inadvertent differences are corrected.

## An ethnic origin item

As some of you have suggested, we have developed a model question on ethnic origin for States with small Hispanic populations to use in lieu of the Hispanic origin item. To be as comparable to the Hispanic origin item as possible, it is necessary that examples for the three prominent Hispanic subgroups come before those for non-Hispanic groups. This item should always proceed the race item on the certificate and the mother's worksheet. Also please note that examples given in the ancestry item should not include check-box items or examples given in the race item.

Ethnic Origin–Cuban, Mexican, Puerto Rican, Arab, Italian, Hmong, Ukranian, etc. (Specify)

## What is the NPI?

Several commenters requested clarification the meaning of the National Provider Identifier (NPI) The NPI is a unique identification number for health care providers that will be used by all health plans. Health care providers and all health plans and health care clearinghouses will use the NPIs in the administrative and financial transactions specified by HIPAA. Final guidance on the format and structure of the NPI will be issued by HCFA. For more information see http://www.hcfa.gov/stats/npi/faq3%2D99.htm

## Facility Name/Births occurring "en route"

Several reviewers noted that the instructions in the new specifications were different from those in the current NCHS handbook. The draft instructions <u>are incorrect</u> and will be revised.

#### Maternal height

In response to your comments, we have modified instructions for this item. We now recommend that the electronic systems accept height in both feet and total inches and that hospital staff <u>not</u> be asked to convert feet to inches.

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#### Use of the term "maiden name"

It became evident over the course of the Panel discussions that the term "maiden" is considered pejorative by some women. As a result, the panel determined that it should not be used on the standard certificate.

## <u>Time of birth</u> We plan to collect the time of birth in the NCHS data set.

## Coding for American Indian

A coding structure for tribes will be included with the specifications. The question asks for the name of the "enrolled or principal" tribe so no more than one tribe should be coded.

## The use of derived variables for the Date of the Last Menses(LMP)

A derived variable was designed to edit the Date of the Last menses. The derived variable estimates gestational age in months and does not use the day of the month of the last known menses because of the high proportion of records for which this information is missing. Methods to impute the missing day for State files will be included at a later time.

I want to thank you again for your continued assistance with this phase of the implementation process. We will keep you informed on our progress in implementing the new standard certificates and will be posting all relevant information on the revision on our web site. If you have further specific questions about these comments or the specifications please contact Joyce Martin (301) 458-4362 JAMartin@CDC.GOV or Stephanie Ventura (301) 458-4547 <u>SVentura@CDC.GOV</u>.

Sincerely,

Mary Anne Freedman Director Division of Vital Statistics