

# **Collaboration for Analysis of New Birth Variables**

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## **Abstract**

The purpose of this project is to provide a method for states to appropriately analyze and publish new data items included on the 2003 revised Certificate of Live Birth. As a member of the National Association of Public Health Statistics and Information Systems (NAPHSIS), I worked to create a way for states to collaborate in creating merged state datasets and analysis plans for the variables added to the birth certificate. Results will be published nationally and presented at the Annual Meeting of the NAPHSIS. In the past, the National Center for Health Statistics (NCHS) had the responsibility for publishing these items. Due to a NAPHSIS Resolution (Attachment A) passed in 2005, NCHS was not allowed to publish these items. Both groups were aware of the need to publish the items for use in public health research, but had not been able to reach an agreement. After much discussion, a new motion (Attachment C) was passed by the NAPHSIS membership in June 2007 to allow collaboration between the two groups for publication. This process is still in progress.

This project provided an opportunity to improve communication, organization and short and long term planning. Good communication was needed to talk with both NAPHSIS members and NCHS about the importance of publishing the data for public health. Organization was needed to plan the conference calls with the NAPHSIS sub-committee and NCHS participants and keep all information available for reference quickly when questions arose during those calls. Short and long term planning were used for the conference calls and the requirements for further collaborative research through creation of a Memorandum of Understanding (MOU) (Attachment E) between the groups. This project has made me step out of my 'comfort zone' and into a leading role.

## **Introduction/Background**

All states and jurisdictions within the United States provide vital event data to the National Center for Health Statistics (NCHS) through the Vital Statistics Cooperative Program (VSCP) and receive payment for this data to help fund the timely collection and quality of this data. In 2003, the NCHS provided recommendations for revising registration documents for birth, death and fetal death events. Along with the revision, they recommended re-engineering the entire process of filing records, monitoring quality of information and issuing certified documents. The importance of re-engineering systems was stressed over the revision of the certificates related to the above mentioned vital events. Many states were still using a paper system for registering vital events. Changing to an electronic system for all vital events would be a huge undertaking. Initially, the NCHS believed that there would be funding associated with these recommended changes. The funding did not come, so states were left to struggle through re-engineering and revision on their own. Due to budget and resource issues, the revisions were not made by all states at the same time as had happened with the 1989

revision process. Some states revised their forms only, some created only new electronic systems and some did both simultaneously. States have also varied in the order they revise their birth, death and fetal death forms. This has created significant issues with the consistency and availability of national data. Only nine states had revised their Certificate of Live Birth in 2003 or 2004 data years.

In 2005 the NCHS informed the NAPHSIS that they had not been funded to pay for data provided on the new items collected on revised certificates. This prompted a resolution (Attachment A) that was passed by the NAPHSIS membership to provide the data on new items to NCHS only as a loan. This was an attempt to force funding for the new data that were being collected. They could analyze the data for quality assessment purposes and could only present analysis at the NAPHSIS meeting or the VSCP project directors' meeting. They could not publish the data in any manner.

In late 2005, the NAPHSIS statistics committee took on the task of doing a simple analysis of the data from states who had revised their birth certificate in 2003 or 2004. At that time, a sub-committee was formed that included some members of the statistics committee, as well as all states who had revised. A project plan (Attachment B) was created for analysis of new items in three phases. For the first phase 2004 aggregate data was collected from states who had revised in either 2003 or 2004. Using this aggregate data, simple tables were constructed to look at the new variables. Phase II of the project plan was to produce a publication using 2005 birth data, and Phase III was to begin analyzing new data items from revised death certificates and reports of fetal death. The first phase brought to light the limited ability of NAPHSIS to create a merged multi-state dataset (not just aggregate data) and do a true analysis (not just tables with numbers and percentages). Merging state data has many issues including how to handle confidentiality issues related to laws in different states, where to house the data securely, how to format the data so that it is consistent for analysis, and how to get data from multiple states in a timely manner. Tables of numbers and percentages can be helpful as a first look at data, but with new variables there should be quality checks and comparisons to previously collected items to ensure the data provide an accurate representation of the population. These limitations are not due to lack of ability among NAPHSIS members and staff, but the lack of time and resources states could put to this project in addition to their individual state responsibilities. This data is important to public health research and needs to be published so that researchers are aware of its quality and availability.

### **Project Description, Objectives and Methodology**

The original objectives of this project were to create a new project plan for data analysis, create a framework for merging datasets to a common format, and present new analysis at the NAPHSIS annual meeting. As the project moved forward, some unexpected things occurred changing the objectives somewhat. The objective of presenting new analysis at the NAPHSIS annual meeting is still in place, but a change at the 2007 NAPHSIS/VSCP meeting created a new overarching goal for NAPHSIS members to publish new data items in collaboration with NCHS. The new objectives to reach this goal include creating a sub-committee of the NAPHSIS Statistics Committee for the purpose of collaboration

with NCHS and creating an MOU between NAPHSIS and NCHS that would guide research and publication of the new data items.

## **Results**

In fall 2006, I volunteered to participate in a sub-committee of the NAPHSIS Statistics Committee to analyze new data items from the 2003 revised Certificate of Live Birth. Some simple tables had been presented at the NAPHSIS Annual Meeting in June 2006. These new data items needed further analysis, as well as quality checks to ensure the accuracy. Due to the 2005 NAPHSIS Resolution, NCHS was not allowed to publish the new data items. Because of my interest in the new variables, I became the chair of the New Variable Analysis Sub-Committee. We had several conference calls to discuss how we were to follow through with the project plan (Attachment B) created the year before. Phase I was to present aggregate data in table format at the 2006 NAPHSIS Annual Meeting, which had taken place in June. According to the plan, the goal for Phase II of the project was to prepare data in a format similar to the format used by NCHS to present information on new data items following the implementation of the 1989 revised birth certificate (see National Center for Health Statistics. Advance report of new data from the 1989 birth certificate. Monthly Vital Statistics Report; vol 40 no 12, suppl. Hyattsville, Maryland: Public Health Service. 1992). This would require a dataset with record level data, which presented many difficulties. Creating a multi-state dataset would require merging multiple states' data while keeping straight confidentiality requirements for all the individual states involved, keeping the data secure, and putting the data into a consistent format. In addition, the individual states would have to provide their data in a timely fashion to allow time for the analysis and creation of the report before the meeting in June 2007. Early in 2007, the sub-committee with discussions with the full Statistics Committee decided that this report was not possible by June 2007, with the limited resources available from the states and NAPHSIS. This was communicated to the Executive Committee of the association. It was decided that NAPHSIS must present something related to the new items at the annual meeting, since it would be a joint meeting between NAPHSIS and NCHS.

In June 2007, I presented more aggregate data through tables in a break-out session of the annual meeting (Attachment D). This break-out session also included three other presentations by NCHS staff using the new data items. To say the least, it was a bit embarrassing to present so little when NCHS was presenting more thorough analyses. After some discussion with the chair of the Statistics Committee, rather than focus on the data I made the focus of my presentation the limitations of NAPHSIS analyzing data and the importance of publishing the data through various collaborations. The next to the last slide said "Use the Data!". This had a great impact on other NAPHSIS members. There was much discussion at the business meeting later in the day. Concerns regarding the absence of additional funding for data by NCHS were voiced, as well as concerns regarding the importance of publishing the data for public health. Members from various states went to the microphone and voiced their opinion. I made it to the microphone and pointed out to the membership the states' responsibility to public health. If the states sit on the data, it will impact public health research.

At the final business meeting, a motion (Attachment C) was made to have the NAPHSIS Executive Committee approach NCHS about collaboration on analysis of the new data items. This motion passed, though narrowly.

In August 2007 the NAPHSIS Statistics Committee had a conference call including all its members and asked for volunteers for a chair and members of the NCHS Collaboration Sub-Committee. I volunteered to chair the sub-committee and several members volunteered to participate. Then the revised states were contacted to ask for representatives. The responsibility of the sub-committee was to draft the MOU, communicate with states that have revised their Certificate of Live Birth about the progress of the MOU and collaborations, and participate in research activities.

At the time of the conference call, there were two requests from NCHS for a state co-author to collaborate on two separate articles, one in the journal Pediatrics and the other the NCHS 2005 Expanded Data Report. I volunteered to work on the Pediatrics article and another member of the subcommittee volunteered for the Expanded Data Report. The process of drafting the MOU began in September and the final draft (Attachment E) went to the NAPHSIS Executive Committee at the end of October. It is now being reviewed by the revised states. If accepted, it will then go to NCHS for signature. The MOU outlines the creation of a committee called the Collaborative Research Committee (CRC) containing two co-chairs, one from each group, and three additional members from each group. The CRC will be charged with review and approval of research, analysis, and dissemination of all national level data. In detail, the CRC will oversee research utilizing the new data items, by

- Planning for the analysis of data,
- Assigning NAPHSIS members and NCHS staff to conduct and review data analyses,
- Preparation of all reports and manuscripts,
- Dissemination of data and research results, and
- Authorship citations and acknowledgments.

This project is in progress. Acceptance of the MOU by NCHS with publications of the new data items and the presentation of analysis at the 2008 NAPHSIS Annual Meeting have not yet occurred, but seem very promising.

My mentor was very encouraging with this project. She helped me develop the topic, reviewed the proposal, and reviewed the final draft. She helped push me to step out of my comfort zone to show my leadership skills.

## **Conclusion**

There are several successes for this project. There is more trust between the NAPHSIS and the NCHS, there are collaborations already in place, and excitement from many on moving forward with publication of the new data items. The publications will make

researchers aware of the usefulness of the population based data collected through the registration of vital events. The collaboration between the NAPHSIS and the NCHS can improve quality of the data and research produced. States can provide their expertise on collection of the data and limitations of its use, while NCHS provides experienced researchers with access to combined datasets needed for analysis. If this relationship is developed and nurtured, it can result in many useful public health research projects in the future.

## **Leadership Development**

This project helped me to improve several leadership skills. It helped me to improve my confidence by asserting my thoughts and ideas. By stepping out of my comfort zone and into a leadership role with a national association, I forced myself to give feedback and assert my ideas. I am much more comfortable playing a supportive role, so this was a change for me. Additional areas of leadership development were short and long term planning. Because my project was a collaborative effort among nationwide participants, I had to provide clarity and direction from my perspective on the short and long term goals that would be positively received by the NAPHSIS and the NCHS.

A specific example of asserting my thoughts is when I went to the microphone during the NAPHSIS business meeting. Many of the people in the room have worked in the area of vital statistics for 10 to 20 years. I felt very strongly about this issue, so I worked up the courage to go to the microphone. Later the NAPHSIS Executive Director and a couple of other long-time, active members provided words of encouragement to let me know they were glad that I spoke up. This really gave me an extra boost of confidence.

Another skill that this helped me to work on was communication. The chair of the statistics committee and I worked on the first draft of the MOU before taking it to the sub-committee. We were both very clear about what we wanted in the MOU. The Statistics Chair was not on the call when I presented it to the sub-committee, and I quickly realized that I was not communicating it to them well. After a few questions, I summarized the intent of the MOU and got some better feedback from the members. This was an excellent experience for me. It caused me to rethink how I communicated to others, which ultimately led to a different approach that produced positive results.

My organizational skills also improved as a result of the coordination required for this project. Because of the hectic work schedules of the committee participants, scheduling conference calls as well as communicating with NCHS staff truly tested my ability to be organized and make the best use of everyone's time, including my own, in order to accomplish the goals of the committee.

Overall, SEPHLI and my leadership project have made me more self-aware and more willing to step out of a supportive role to take the lead. I now feel more confident in asserting myself professionally. I also gained a much deeper understanding of my leadership style, and learned the areas and skills I needed to focus on to make me a better leader.

The leadership skills that I improved during this project will serve me well in my professional development at my agency. In my current position as Director of the Division of Biostatistics, having the ability to communicate clearly and concisely is an asset as I work with my staff to implement ongoing changes within our office. I am constantly juggling multiple projects and personnel issues, and my improved organizational skills will result in much better utilization of my time. Time-management is critical to my staff as well, and they will reap the benefits of this improvement. My leadership experiences over the past year have helped me better understand the skills needed to be a successful leader. Leadership involves many challenges, but I now have tools to work through those challenges.