

**Response: Kirby Russell, Florida Birth Defect Registry (FDoH)**

Nancy,

Our work at USF supports the Florida Birth Defects Registry (FDoH) as well as a variety of research projects focusing on birth defects epidemiology and health services utilization as well as factors associated with pregnancy outcomes and long-term health of women who give birth. We use AHCA data extensively, usually analyzing datasets that result from record linkage of AHCA records internally to AHCA as well as with other FDoH databases. I have tried to respond to each of your questions below.

*We are surveying various state agencies regarding their linkage requirements, if any, across different data sets or within the AHCA data set.*

- *What applications/programs/studies are supported with AHCA discharge data?*

The Florida Birth Defects Registry relies heavily on data from the AHCA discharge database, in fact well over 80% of our cases, and for some birth defects over 95%, come exclusively from the AHCA records. **FBDR was mandated by Florida statute, and part of the political agreement that led to its enactment was that hospital reporting burden would be reduced because AHCA hospital discharge records would be acceptable as a form of reporting.**

However, we rely heavily on the SSN/Infant Linkage element to link the records identified with birth defects to their respective vital records documents. Without this data element, it would become very difficult for the FBDR to be created in a timely manner, and might result in FBDR needing to request additional reporting from hospitals to update the registry.

- *What data sources do you utilize other than AHCA data?*

We use Florida vital statistics, occasionally data from the Florida Children's Medical Services program, PRAMS, the Florida Cancer Data System, and related data sources. We also have strong interest in integrating Medicaid and SCHIP records with these data, although we are not presently engaged in projects related to these linkages.

- *What data elements are required for linkage from each data source?*

It is important to properly link each birth defect report to its respective vital records documents. We rely on names (child, mother, maiden, etc), dates (child birth date, mother birth date, date of service), and SSNs (maternal for first year of life, child thereafter). We also use facility codes, and typically compare other fields to validate the quality of the resulting linkages. However, for AHCA hospital discharge records, we rely almost exclusively on the SSN/Infant linkage element.

The linkage work is done internally at FDoH, and the SSN/Infant Linkage data are not released to researchers.

- *What is the impact if the SSN/Infant Linkage element is eliminated from the AHCA data source?*

Loss of this data element would hamper the creation of the annual FBDR dataset significantly, and might require FDoH to use its data gathering authority to require direct reporting of birth defects cases to the registry. As noted above, when FBDR was created, part of the political agreement was that cases could be reported through newborn and infant hospital discharge summaries, which would then be linked to vital statistics records to create the registry. The linkage requires this data element for efficient

processing. Without it, additional personal identifiers would need to be obtained from the hospitals to ensure valid and reliable linkage of the records.

- *Do you use other methodologies/algorithms that require SSN/Infant Linkage?*

Our primary activities involve the creation of the FBDR and the linkage of AHCA records into longitudinal composites for women delivering, and infants with selected birth defects and a control group.

Florida has also been involved in a record linkage activity with the Centers for Disease Control and Prevention involving the linkage of data from the SART national assisted reproductive technology database and Florida vital statistics records. Once linked, this becomes the platform for integration of other data, including the FBDR, and plans are in place to also link the FCDS. This work would be hampered at least to some extent by the loss of the SSN/infant linkage data element.

- *Additional comments or concerns?*

In my opinion, AHCA should continue to collect the SSN/infant linkage data element. In fact, the linkages that result are highly beneficial for hospitals, patients and families, health care providers, public health agencies and community organizations, and are the core of our efforts to ensure optimal maternal, infant and child health outcomes for the citizens of the state of Florida. The benefits of having this data element far outweigh hospital concerns about the cost of providing the data, and as noted, FDoH could compel hospitals to file birth defects case reports with this information directly to the FBDR to enable it to fulfill its statutory obligations under the statute that created the FBDR.

Thank you for the opportunity to provide my perspectives on this issue. I would be happy to discuss this further,  
Russ

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