

## Prenatal Data Task Force Comments and Questions

DHSS annually links calendar year birth data to MO HealthNet files to provide a report for a set of 12 birth-related indicators<sup>1</sup> that shows the data by region and specific managed care plan. The report is usually run about nine months after the end of the calendar year. Potentially, this data could be extracted to provide each plan with the birth data for their respective plan's births. 2009 data is currently available while 2010 data will not be available until late 2011.

The release of Missouri birth record level data is allowed under certain conditions by Missouri State Statutes and Regulations. See <http://www.dhss.mo.gov/LiveBirths/> (Data Release Policy) for a more detailed explanation of these statutes and regulations. The statutes only apply to vital events occurring in Missouri. The records of vital events occurring in other states to Missouri residents are the property of the state where these events take place. So while DHSS can use these non-Missouri recorded vital events for statistical reporting, the individual records cannot be released to other entities without the other state's approval. (This affects 4-5% of Western Region MO HealthNet births).

In order to meet the conditions of these Statutes and Regulations, it is necessary for DHSS to have more information regarding exactly what birth data items are needed and exactly how this data will be used by the Plans. See <http://www.dhss.mo.gov/LiveBirths/> (Data Elements) for a list of data items on the 2009 birth file. The stated purpose of the Task Force "to contribute to improved health plan analysis of birth outcomes" is a little too vague. Does this mean examining the 12 birth indicators from the current report by additional variables from the birth file such as age, race, county of residence or education, or does it mean something else?

It seemed to be the consensus of the Task Force that identifying information (names, dates of birth, DCN numbers, addresses etc.) was needed, but it was unclear why or how.

The use of identifying information is problematic and may require the need of an Institutional Review Board review. Is identifying information needed to link to other data sources? If so, the method and purpose needs to be explained in detail. Some Plans indicated they would be used for follow-up, but this seems unnecessary since the birth addresses would be old and unreliable by the time the Plans could receive them. It was also indicated that they could be used in conjunction with HEDIS. But the only birth indicator of the 12 in our standard report, that we are aware of, is early prenatal care, and this is collected in a completely different way for HEDIS.

Once an agreement is reached as to what data items are needed and for what purpose, each Plan will need to sign an agreement that also spells out each Plan's confidentiality protections. These include such assurances as (1) No other agency or individual will be given access to the data (2) The data will be properly disposed of when finished with it (3) No attempts will be made to contact family members unless approved by the State

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<sup>1</sup> HEDIS Indicators: 1) C-sections, 2) VBAC, 3) Adequate prenatal care, 4) Early prenatal care, 5) LBW, 6) LBW-L3 delivery, 7) VLBW-L3 delivery, 8) Smoked while pregnant, 9) Spacing LT18 months, 10) Mom LT18 years, 11) Repeat teen births, 12) Prenatal WIC.

Registrar (4) No attempt will be made to link to other data sets unless approved by the State Registrar and (5) The use of these data will be strictly limited to the proposed purpose.

**Questions:**

1. What is the specific reason for requesting birth data? What purpose will be accomplished? Enough information is needed to make a determination whether the request is for research, public health practice, or administrative purposes.
2. Data for what months or years is requested? (Please provide beginning and ending dates)
3. What specific data elements are requested and why? How will they be used?
4. What will the duration of the project be? How will the Task Force know when the project is complete?
5. Does the proposed project involve follow up or possible contact with individuals identified in the data? If so, review and approval by the MO DHSS Institutional Review Board is required.
6. Is this a one-time request for data, or will additional data be requested before the project is complete?
7. What geographic boundaries, if any, define the data? What geographic detail is needed for the project? Note: only data on Missouri recorded events can be released. That is, Missouri resident births and deaths taking place in another state cannot be released. Geographic data below the county level is considered identifying information in some circumstances.
8. Will the data be linked to any other data or files? If so, how will the linkage be done and what data will it be linked to?
9. What methodology will be used to accomplish the project objectives?
10. Who will have access to the data if the request is approved?