

Background on the Child Health Data Systems Integration and Improvements Work Group

The Child Health Data Systems Integration and Improvements Work Group was tasked with addressing data systems improvement issues in relation to existing NBS, clinical genetics, and birth defects databases, as well as integration of these databases into children's health information systems such as vital records, immunization, lead screening and birth defects registries. As written in the original grant application to the Health and Human Resources Administrative, the initial objectives of the work group were to

1. Identify barriers and facilitators for implementing both short-term and long-term outcome databases for NBS/genetics
2. Highlight state initiatives to develop child data registries and integrate data, particularly in regard to NBS and birth defects monitoring
3. Identify examples of customer and stakeholder analysis, mapping child health data environments, and strategies for obtaining executive sponsorship
4. Showcase current NBS data management technology within the region and nationally including examples of web-based programs such as DocSite that include both a population planner and a patient planner component
5. Identify a list of data elements of common interest to states within the region

Examples of potential outputs resulting from the work group include

1. Development of common data elements and/or outcome indicators for region
2. Sharing of linkage methods and algorithms
3. Review of available software tracking systems
4. Technical assistance to address programmatic data needs within the states
5. Facilitating presentations/information sharing with states outside the region

The Work Group has been meeting by conference call since fall of 2004. During the fall of 2004, the group completed a survey of data collected within different program areas and indicated whether "planning", "start up", "near completion" or "maintenance phase" of database development. The state representatives also indicated which of the databases were in electronic format and which were integrated at that time. The state leads also identified issues that were of interest for collaborative efforts during the period of the grant.

During the monthly conference calls, the group decided to focus on identifying data elements in two data systems related to genetics due to the focus on genetics within the overall regional collaborative. The group decided to focus on birth defects databases (or registries) and newborn screening long-term outcomes databases. As so few states actively collect information on long-term outcomes of children identified through newborn screening, the group then decided to focus exclusively on birth defects registries.

As a result, the Group Lead developed an “inventory” form including questions pertaining to authority for the registry, data collection, aspects of the database, database maintenance, analysis of data, and registry roadblocks. The group felt that by reviewing one database, each state lead could better understand how databases are structured to see similarities and differences in other databases both within states and between states. This would be a crucial initial step in understanding how databases might be improved in anticipation of future both within states and, ideally, between states. Please note that for the purposes of this collaborative effort, the states agreed that specific data within the registries would not be shared due to privacy issues across state boundaries.

Finally, most recently, state leads have been asked to review the data that was collected on the “inventory” form with the individuals within his or her state who initially assisted with providing the information. For those new to the work group, the individual contact for each section should be listed within each section. The contact information of these individuals will not be shared outside the collaborative, as the group decided that each state lead should be the sole contact person for the inventory (to prevent confusion or and additional work by the individuals responsible for aspects of the registry, not affiliated with the collaborative). The state leads are now asked to review their own information, completing sections with ambiguous or missing information, and to complete the “Data Inventory Assessment” form. This form will be discussed at the next conference call. The group plans to develop a peer-reviewed paper based on the work of the group. Additionally, the group decided to complete the initial survey, originally completed in 2004, to assess any advancement (or recession) in progress in the development, improvement and integration of databases within each state and the region.