



**Jeannette B. DeJesús**  
SPECIAL ADVISOR TO THE GOVERNOR  
OFFICE OF HEALTH REFORM & INNOVATION  
STATE OF CONNECTICUT

**DRAFT**

**Statewide Multi-Payer Data Initiative**

February 23, 2012

Meeting Minutes

---

Members: Robert Aseltine, Mary Ellen Breault, Jeannette DeJesús, Kim Martone, Mark Schaefer, Bobbi Schmidt, Bob Tessier

Absent Members: Ben Barnes, Deb Heinrich, Sue Hoben, Jim Iacobellis, Kevin Lembo, Thomas Leonardi, Jewel Mullen, Tom Woodruff, Vicki Veltri

Attended by Phone: Mary Taylor, Rod Bremby, Christine Capiello, Dave Harrington for Tia Cintron

---

**Welcome**

Jeannette DeJesús discussed our proposed legislation, Governor's Bill 5038, and legislative strategy which included a plan to talk with legislators to move the bill forward.

**Review of H.B. No. 5038**

Roberta Schmidt provided a review of the All-Payer Claims Database enabling legislation (H.B. 5038). Mrs. Schmidt explained that the structure of the bill was created with the advice of the Legislative Commissioner's Office. The enabling statute (HB 5038) is folded into existing legislation that initially set up the Office of Health Reform & Innovation and the Work Group (P.A. 11-58). The bill defines the All Payer Claims Database and reporting entities. Reporting entities include insurers and healthcare centers (HMOs) that provide commercial coverage as well as Medicare Advantage and Part D plans. All insurance type entities and TPA type entities are included in the definition of reporting entities. The general statement of purpose requires the Office of Health Reform & Innovation to establish and maintain an All Payer Claims Database for the purpose of providing transparent and public reporting of health care information relating to safety, quality, access and efficiency. The Office of Health Reform & Innovation will oversee initial planning and implementation of the APCD program and ensure reporting entities report for specific purposes. The Office of Health Reform & Innovation or the permanent APCD administrator has the authority to retain consultants as needed. Based on previous work group discussion, it has not been determined where this program will be permanently housed. Consistent with previous work group discussion, this allows the Governor in conversation with the work group, to assign the administration of the APCD in the future. The APCD administrator has the authority to prescribe rules for the operation of the database that are consistent with national standards, and shall establish rules for the time and manner of reporting. Reporting

requirements for the data include measures to ensure data accuracy and protocols for the disclosure of data. The legislation says the Office of Health Reform & Innovation or the assigned administrator shall utilize the data for various reasons in compliance with federal and state privacy rules. The legislation allows for fees to be charged for data access by outside parties. The legislation also creates an Advisory Work Group. Mrs. Schmidt explained, the proposed work group would replace the current working group and be established to provide input on an ongoing basis regarding maintenance and management of the database. The new advisory work group would substitute the current working group and reflect the same membership with additions from the Department of Mental Health and the Office of the Healthcare Advocate. This bill reflects the discussion we had at our last meeting.

### **Privacy & Security in H.B. 5038**

Mrs. Schmidt reported on the Office of Health Reform & Innovation's ongoing investigation into privacy issues. The collection and release of data requires compliance with state and federal confidentiality laws. Increasingly, other state APCD's are collecting direct patient identifiers including Social Security numbers. Mrs. Schmidt explained that the Tennessee statute prohibits collection of protected health information including Social Security Numbers (SSNs) and they are having a difficult time performing the analysis they would have liked with the APCD. Alternatively, the APCD can collect encrypted protected health information like Colorado and maintain full compliance with HIPAA in file transmission. After collecting encrypted files, data can be temporarily de-encrypted to replace the Social Security number with a unique identifier on both claim and eligibility files. In this scenario, the original Social Security Number will subsequently be re-encrypted, and then stored separately in the database for no further use. The Office of Health Reform & Innovation proposes this information as education to the work group and does not reflect a database design decision. The Office of Health Reform & Innovation does recommend disclosure processes that remove detail to the extent that an individual cannot be determined. For further information about privacy, Mrs. Schmidt explained that HIPAA allows limited datasets with omission of social security numbers as well as identifying information like demographic information. We want to design a system that will allow interoperability with other databases while protecting patient privacy.

### **Group Discussion about the Collection of Social Security Numbers**

Bob Tessier explained that insurance companies are not using SSNs as member identification numbers. Insurers are concerned with potential disclosure of SSNs due to the disastrous effect of medical identity theft. Mr. Tessier says the need for the social security numbers is not clear. He understands that APCDs need individual level data to aggregate at the population level but he wants the state to avoid potential difficulty and risk.

Bobbi Schmidt stated that the office is exploring this issue very seriously with great detail. She believes self-funded plans are not using Social Security numbers. There is clarification in group discussion that the carrier can collect the Social Security number but insurers are prohibited to print the SSN on the insurance card. Through the eligibility file for the member and dependents, social security numbers can be used to link files. With limitations of the linkage, the social security number is the universal number used by all payers. Bob Tessier indicated subscriber unique identifiers are different by carrier but enrollment information allows for linkages on other demographic information.

Jeannette DeJesus asked the group to discuss the reasons not to collect SSNs. Bob Tessier is concerned with the disclosure of social security numbers if they are collected. He wants to make sure every person's information is being protected against inadvertent exposures.

Mary Taylor explained that many employers have ceased using SSN for benefit plan enrollment, because companies have their own privacy policies that prohibit sharing SSNs. She agrees, that SSNs makes perfect sense for research data management, but mentions that payers cannot be expected to submit SSNs if they are not available through the employer.

Bobbi Schmidt mentioned that in her experience working for Aetna she is familiar with some self-funded plans that do not provide SSNs to payers. However, despite federal reporting MSP requirements, payers are still getting social security numbers from the majority of employers.

Dr. Schaefer was asked about his experience in collecting social security numbers. He replied that he is required to report social security numbers. Tracking individuals in the DSS warehouse is different than

tracking individuals in an APCD where information is different across payers for the same individual. Also, he stated he is familiar with data breaches. Dr. Schaefer recently received notice of a breach at Yale in which he received a letter of notification and identity theft services. Dr. Schaefer explained it is notoriously difficult to track people using name, DOB, gender and address in a database because people move and change their name with marital status. Therefore he is curious to know what other states have done and how successful they have been with or without collecting SSNs. He would like to know how much error would be introduced by matching in an imperfect way. DMHAS has experience with cross-system probabilistic matching. They have created likelihood arrangements between Department of Labor, DMHAS and DSS datasets to create reliable matches with name and a few other elements. He wonders if 99% of linkages are accurate and 1% are not, how much this effects the quality of our research. Leadership at DMHAS can provide more insight into this methodology which may or may not be professional grade for the type of data management the APCD demands. Dr. Schaefer also says the work group must prepare to discuss this issue with legislators and the public. Commissioner Bremby encouraged the work group to look at other states with significant experience working with the APCD data. Bobbi Schmidt gave an update with ongoing discussions with other states.

### **Group Discussion about Data Management & Probabilistic Matching**

#### Lessons from the CHIN:

Rob Aseltine stated the CHIN database is familiar with data matching logic. He encouraged the group to consider system capacity required to accomplish computations of increased complexity. Complex matching algorithms may require more time and resources to develop. He recommended maintaining consistent, but not increased, awareness privacy of personal information when developing the APCD. He also recommended a design strategy that separates identifying medical claims and other personal information. He explained there is no need to merge the two sets and by segregating them, if there is a breach in the system, there is de-identified claim information or essentially directory information comparable to a phone book or voter registration list.

#### Lessons from other States:

Roberta Schmidt says we are speaking with other states like Maine, New Hampshire and Tennessee. The Office of Health Reform & Innovation is learning what other states are doing to accomplish the match and the limitations with ability to link files across payers for the individual. Rob Aseltine stated that claim data, and data linked to a financial transaction is likely to be high quality and expects 95% accuracy which is more than adequate for research connecting individuals. Tracking their care may need more accuracy.

#### Lessons from the Health Information Exchange:

The group discussed the Health Information Technology Exchange matching algorithm and how it relates to the APCD. The legislators are concerned with privacy protections and the security of the database and control of the data in terms of opt in/out. Ms. DeJesús explained the concern has been expressed in general terms only so it is important that this work group be able to recognize what the privacy issues actually are. Bobbi Schmidt reported on a previous discussion with Vicki Veltri and Ellen Andrews about privacy in the Health Information Technology exchange and future interoperability with that exchange given an individual opting out of the HIE. Ms. DeJesús would like a system that does not impede interoperability between systems. The HIE offers an Opt-out option. In light of this, the APCD should incorporate limited disclosure policies. Continue this discussion in the next meeting.

#### Questions regarding APCD enabling legislation (H.B. No. 5038)

Mr. Tessier asked about line 149 in the legislation, item 13(L) regarding disclosures to “any” state agency, insurer and other external parties. He wanted to know whether there will be protocols to evaluate external parties’ qualifications and intent with the data. Mrs. Schmidt answered, “yes”. Mrs. Schmidt replied that the Legislator Commissioner’s Office clarified this concern in the language. The legislation says data access and release is subject to protocols defined for specific groups. Ms. DeJesús suggested clarification of the language of this section of the legislation in order to preserve our intent and meaning.

Kim Martone asked whether state agencies will be charged a fee for data access. Mrs. Schmidt explained that the legislation creates a placeholder for the authority to impose fees, but with advice of this group we would decide what those rules would be. Ms. Martone asked “On page 8, where the legislation lists the agencies, should the Department of Children and Families be included in that?” Mrs. Schmidt replied we should add DCF and the Technology Officer as well.

Bob Tessier and Mrs. Schmidt discuss the potential availability of Medicare experience data to APCDs. Mr. Bremby stated he didn't know the answer to this question. Mrs. Schmidt reported that there is an effort to make Medicare data more available to APCDs. Commissioner Bremby said he has not seen the data yet, but he expects it to be aggregate and not individual level.

Rob Aseltine proposed the possibility to share APCD information with the CHIN database in order to leverage CHIN's capacity to communicate across data, analytic powers and publicly accessible portal for data requests.

#### Update on the Status of the APCD enabling legislation (H.B. No. 5038)

Ms. DeJesús provided an update on the status of the legislation. The Legislation will be going through the Public Health Committee first and the Office of Health Reform & Innovation will be meeting with leadership of each committee communicating information about the APCD. She asked for members of the work group to submit testimony in support of the legislation. She encouraged us to educate the public and legislators about the value of the APCD.

#### Update on the Statewide Multi-Payer Data Initiative Plan to Implement an All-Payer Claims Database

Laurie Graham provided an update on the Statewide Multi-Payer Data Initiative report which includes content available on the website and will be reflective of the work group discussions. Mrs. Schmidt asked the group to suggest the best way to provide feedback on the report. Ms. DeJesús suggested emailing Laurie Graham with thoughts about the report so it can be finalized as soon as possible. The Office of Health Reform & Innovation expects to submit this report to the group by the beginning of the next week. There is a draft currently in review by the Office of Health Reform & Innovation.

#### Update on Funding & Budget Assessment

Ms. DeJesús provides an update on funding available through the Health Insurance Exchange. We are structuring our strategy to ensure the Exchange is the first user of the APCD. Ms. DeJesús announced that the Health Insurance Exchange Board supports initial start-up funds for the APCD to be made available through the Level 1 or 2 Federal Exchange Grants. These monies will be used to hire consultants to assist in our budget planning for the APCD.

#### Update on Use Case Interviews

Laurie Graham provided an update on use case discussions that are ongoing. The Office of Health Reform & Innovation is using an interview template to collect information from individual stakeholders. These interviews will help the Office of Health Reform & Innovation understand stakeholders' business needs in order to design the APCD to reflect their unique requirements.

#### Public Comment

Mary Taylor asked "If the Exchange is going to be the first user of the APCD what is the timeline for the implementation of the APCD?" Mrs. Schmidt and Ms. DeJesús responded that The Office of Health Reform & Innovation has targeted the initial release at the end of 2013 to be available to the Exchange in the beginning of 2014.

With no further comment. Ms. DeJesús encouraged the public to address Bobbi Schmidt or Laurie Graham with questions if not comfortable speaking on record with the work group.

Ms. DeJesús thanked the group for their contribution and invited the work group to visit the website and see an update on the next meeting schedule.

The meeting adjourned at 10:30 a.m.