

Special Meeting of the All-Payer Claims Database
Subcommittee on Data Privacy, Security, and Confidentiality
Meeting Minutes

Date: Thursday, November 3, 2016
Time: 12:00 pm – 2:00 pm
Location: Legislative Office Building, Room 2B

Members Present

Robert Scalettar (chairperson), Robert Aseltine, Demian Fontanella, James D. Iacobellis, Matthew Katz, Jean Rexford (via GoToMeeting), Shawn Rutchick (via GoToMeeting), Victor Villagra, Joshua Wojcik

Members Absent

Tracey Scraba

Other Participants

Tamim Ahmed (Access Health CT), Susan Rich-Bye (Access Health CT), William Roberts (Shipman and Goodwin), Matthew Salner (Access Health CT), Ryan O'Neil (Access Health CT)

I. Call to Order and Introductions

Dr. Robert Scalettar called the meeting to order at 12:05 pm. Introductions were made. Dr. Scalettar asked for a motion to approve the minutes of the previous meeting of the subcommittee. Dr. Robert Aseltine motioned. Matthew Katz seconded the motion. The motion passed unanimously.

II. Public Comment

There were no public comments.

III. Discussion on Current Data Release Policy and APCD Enabling Legislation

Susan Rich-Bye led a discussion about the current data release policy as it is set forth in state statute. CGS § 38a-1091 and § 38a-1090 provide for the disclosure of de-identified data by the APCD to state agencies, insurers, employers, health care providers, consumers of health care service, or researchers for the review of such data as it relates to health care utilization, costs or quality of health care services pursuant to 45 CFR 164.514. APCD Privacy Policy and Procedure approved by Board of Directors on February 8, 2016, sets forth the policy and procedure for the release of data by the APCD. Data may only be released when release is consistent with APCD legislation and the Policy, and for legal and public purposes.

IV. Difference between De-Identified Data and Limited Data Set (LDS)

Tamim Ahmed laid out the differences between de-identified data and a limited data set. Differences include that a limited data set has a member's date of birth, ZIP code, and dates of service. De-identified data includes year of birth, year of service, and the first three digits of a ZIP code if the total population of all ZIP codes with those first three digits totals more than 20,000 people; if the total is 20,000 or fewer, than the ZIP code is listed as "00000." Both datasets have an anonymized member ID.

V. What is the Case for Using LDS: Pros and Cons

Dr. Ahmed next presented the positives and negatives when using a limited data set. Positives included using dates to examine utilization patterns, complications or unanticipated effects due to treatment, hospital readmissions, drug complications, and episodic view of costs and utilization by applying clinical groupers. Negatives included that dates may enable patient re-identification, increased risk of re-identification with smaller population in a ZIP code area. Additionally, an inadequate data use agreement may pose a risk of data breach and re-identification. Dr. Scalettar asked if none of the pros

made use of date of birth. Dr. Ahmed mentioned date of birth would be very important when doing neo-natal research. Matthew Katz asked if the Data Release Committee would be able to make the determination whether a requestor needed date of birth or if year of birth would be sufficient. William Roberts stated the current policy requires the Data Release Committee to release only the minimum required data. Dr. Ahmed stated that changing date of birth to either age or year of birth is a simple matter technologically speaking.

In regards to the cons, Mr. Roberts pointed out reviewing a requestor's infrastructure, experience, and training with regards to the ability to manage a limited data set is part of what the Data Release Committee will do. Dr. Aseltine said we just need the assurance the requestor can handle a limited data set along with reviewing their policy on data storage, encryption, and protection. Mr. Katz recommended that this be the formal policy for all requestors.

VI. How Are Other APCDs Using LDS: Best Practices

Dr. Ahmed presented what is being done with limited data sets by APCDs in Colorado, Maine, and Massachusetts. Uses included analyzing emergency department visits non-traumatic dental care, analyzing health care rates in rural areas, conducting volume and service use analyses for hospitals, studying medication-adherence rates for patients with chronic diseases, examining high-deductible plans, and assessing susceptibility to air pollution.

VII. Next Steps

Dr. Scalettar led a discussion about what comes next. Joshua Wojcik asked if the staff of the APCD would alert the Data Release Committee when there was a potential risk with a limited data set having a small cell problem. Dr. Ahmed said that they would. Dr. Aseltine was against the suppression of data by the APCD and expressed concern that some rare medical events were some of the most expensive. Mr. Wojcik expressed his desire to ensure that the most minimal data required is always released. Dr. Aseltine said there will always be small cell problems but that, as a counterweight to that, requestors have to be qualified to handle the data and if they mishandle it, there have to be consequences. Mr. Katz agreed with both ideas, wanting to limit small cell problems as much as possible but still vet requestors as thoroughly as possible. He also asked if there was a way to validate what a requestor states on a data use agreement. Susan Rich-Bye said the agreement allows for verification. She also stated the CEO of Access Health CT has a final veto over any data request. Demian Fontanella asked if the enclave model of data access, where data is only accessed while physically at Access Health CT and no data is removed from the facility, is a method of minimizing risk. Dr. Ahmed responded that the enclave model is for when a requestor is not able to properly safeguard data. Jim Iacobellis said the enabling legislation allows for the broad use of data by a broad range of requestors. His only concern was to ensure there are enough protections to outweigh the cons and with the Data Release Committee, he believed there were. Dr. Victor Villagra believed the cons to be manageable with the Data Use Agreement and that the pros to releasing a limited data set outweigh the cons.

Matthew Katz put forth a motion, that the subcommittee recommend to the Advisory Group have a discussion on changing the availability of data for use along with information about tied to safeguards and this subcommittee supports making a change to the policy. Susan Rich-Bye pointed out that, ultimately, the change would have to be made legislatively. Dr. Aseltine seconded the motion. It passed unanimously with no abstentions. Dr. Ahmed said this would be on the agenda of the November 10, 2016 meeting of the Advisory Group. Dr. Villagra recommended having list of measures other states have implemented would be helpful to the discussion.

VIII. Adjournment

Robert Scalettar entertained a motion to adjourn the meeting. Robert Aseltine moved to adjourn. Josh Wojcik seconded the motion. Motion passed unanimously. The meeting was adjourned at 1:40 p.m.