



Special Meeting of the Data Privacy, Confidentiality and Security Subcommittee
Meeting Minutes

Date: April 1, 2014
Time: 1:00 p.m. - 3:25 p.m. EST
Location: Holiday Inn Hartford East – Junior Ballroom
100 E River Drive, East Hartford, CT 06108

Members Present: Dr. Robert Scalettar, James Iacobellis, Matthew Katz, Joshua Wojcik, Shawn Rutchick, Demian Fontanella, Victor Villagra, Jean Rexford, Phyllis Hyman, Brenda Shipley, Joan Feldman, William Roberts, Mary Taylor (phone)

Members Absent: Robert Aseltine

Other Participants: Tamim Ahmed, Robert Blundo, Christen Orticari, Matthew Salner

I. Call to Order and Introductions

Dr. Robert Scalettar called the meeting to order at 1:00 p.m. Dr. Scalettar provided a brief update to the subcommittee. Members introduced themselves.

II. Public Comment

Ellen Andrews urged the subcommittee to consider implementing an opt-out policy similar to the model in Rhode Island, which is in the process of implementation. Ms. Andrews read aloud the letter that she distributed to the subcommittee via email.

III. Approval of Minutes for the January 23, 2014 Meeting

Dr. Scalettar indicated that the edits and revisions provided by the subcommittee had been incorporated into the previous meeting minutes. **Dr. Scalettar motioned approve the January 23, 2014 meeting minutes. Mr. Iacobellis seconded, all in favor voted, and the motion was passed unanimously.**

IV. Revised Committee Charge Language

Dr. Scalettar announced a modification in the subcommittee charge language based on the commentary from the prior meeting. Dr. Scalettar reiterated the concern raised by Matthew Katz regarding the narrow population addressed in the charge language, which contrasted the goal to protect broader population. Dr. Scalettar suggested that the issue be addressed by replacing PHI, an exclusive term, with individually identifiable information and noted that the change could be observed on the third line of text in the second slide. Mr. Katz expressed that the revision successfully and succinctly remediated the issue. Jean Rexford asked whether the new language covered outlier practitioners and would prevent access to their information. Mr. Katz indicated that the topic should be discussed at a later time. Ms. Hyman suggested that the subcommittee develop a definition for the term individually identifiable information to reduce ambiguity. Dr. Scalettar noted that the purpose of the subcommittee was to develop the procedure for creating ground rules that ensured the privacy, confidentiality and security of APCD information, which required legal support for accurate definition of rules and regulations. Joan Feldman stated that during her review of the APCD enabling legislation, charter, and previous meeting minutes for the APCD, all documents appeared to lack consistent terminology to communicate the semantics of

the revised charge language. Ms. Feldman commented on the potential need for more than one term to describe this content and encouraged further discussion regarding the development of this terminology. Ms. Feldman recommended the edited language be changed from personally identifiable information to the sole term information for the purpose of the charter. Ms. Feldman suggested the inclusion of additional terminology with specialized definitions in policy and frequently asked question (FAQ) documents and the subcommittee indicated their agreement. Mr. Katz remarked that broader language was sufficient for the purpose of the charge.

Victor Villagra opined that the redacted charge needed revision to indicate the subcommittee aim to create transparent process in addition to policy. Mr. Katz commented that transparency dominated the subcommittee approach for decision making in terms of sharing data and conveyed agreement with statement by Mr. Villagra when remarking that the language remained misaligned with aim. Ms. Feldman discussed the importance of balancing accessibility with privacy and security of the data in response to the comment by Mr. Villagra. Mr. Katz conveyed his concern about the appropriateness of the terms limits and boundaries, and offered requirements and restrictions as a terminology to replace limits and boundaries. Robert Blundo stated that the recommendations discussed by the committee would be drafted by Access Health Analytics to reflect the discussion and then provided to the workgroup prior to the next meeting to allow for collaborative revision.

Mr. Rutchick raised a concern in the content of the third bullet, which tasked the subcommittee with the "preparation of a functional data use agreement." Mr. Rutchick commented that more than one data use agreement may be required depending needs and qualifications of various requestors. Dr. Scalettar indicated his agreement with the statement by Mr. Rutchick and noted that the need for multiple data use agreements could be inferred from the charge.

V. Legal Issues Concerning Data Privacy and Security

Dr. Scalettar introduced the next agenda item regarding legal issues in data privacy and security. Dr. Scalettar noted that the discussion was initiated when Mr. Iacobellis and the Hospital Association questioned whether the APCD had status under HIPAA. Dr. Scalettar continued to explain that the deliberation catalyzed APCD engagement with Ms. Feldman and Mr. Roberts, who have since joined the workgroup and begun the iterative process of providing legal clarification. Dr. Scalettar stated that the legal counsel identified the APCD as a non HIPAA-covered entity governed by state legislation. Mr. Rutchick posed the question of whether state agencies, such as OCAH and DSS, would be allowed to only obtain solely deidentified data and no patient identifiable content. Ms. Feldman indicated that this speculation was correct provided the current statute language and suggested that legislators may not have intended it to be extremely self-limiting in translation. Mr. Rutchick remarked that the limitation was problematic in efforts to consolidate data distribution efforts in the state agency network and noted that DPH required APCD data for research. Ms. Feldman specified that the FAQ document was pertinent to issues concerning disclosures by Access Health Analytics to third parties and noted that it did not preclude the exchange from using the data for purposes articulated in the statute. Mr. Iacobellis commented that the severe restriction could prevent researchers from attempting to obtain the data. Dr. Scalettar suggested that the subcommittee draw on their knowledge of stakeholder use cases to drive FAQ inquiry and to then leverage information gained from the discussion by incorporating it into proposals for new or redacted legislation.

Ms. Feldman announced the three categories that fell under the HIPAA definition of a covered entity, which included providers of healthcare services, health plans, and healthcare clearinghouses. Ms. Feldman stated the APCD did not fall into any of the three categories. Ms. Feldman addressed the question of whether the APCD was a business associate under the HIPAA regulations by indicating that the definition of business associate suggested the organization provided a service on behalf of a covered entity; however, the APCD would not be acting as an agent due to its responsibility to fulfill duties set forth by the law. Ms. Feldman explained that submissions were required of payers pursuant to Connecticut General Statute Section 38A-1091b3. Ms. Feldman conveyed that although the APCD was not covered by HIPAA, due to its lack of status as a covered entity or as a business associate, certain HIPAA provisions could apply because the APCD functioned in accordance with HIPAA by way of statute. Ms. Feldman recommended that definitions be cleaned up in the future provided that the APCD had self-imposed HIPAA.

Ms. Hyman questioned whether there could be an occasion where the APCD would be considered a business associate of a covered entity provided that the entity required the APCD to act on its behalf for issuance of reports. Ms. Feldman replied that the answer was uncertain from a policy standpoint. Mr. Katz requested clarification regarding the APCD ability to provide deidentified non-health information. Mr. Roberts responded by referencing 38a-1090(B)(2)-(b), which stated that the exchange could disclose information that was not health information in a manner that would protect the confidentiality of other information as required by law, and conveyed that non-health information be disclosed in accordance with any laws that may or may not apply. Ms. Feldman added there was uncertainty regarding whether the health insurer or provider identifiers were blanketed under this language. Mr. Katz postulated that the provider and insurer names could be provided given this language and acknowledged that not all identifiers, such as those related to the patient level of specificity, could be provided for research.

Ms. Shipley requested that Mr. Ahmed clarify the type of relationship the vendor had with Access Health Analytics. Mr. Ahmed indicated that the analytics vendor could be perceived as the right arm of Access Health Analytics in the sense that the vendor would be working with limited data sets and be held accountable to the same policies established by the state legislature. Mr. Ahmed noted that the contractor had to receive fully identifiable data due to role in deidentification, but would not disclose non-deidentified data. Ms. Shipley asked Mr. Ahmed whether the analytics group would have access to the fully identified data and Mr. Ahmed replied that the group had permission to work with limited data sets.

Ms. Feldman reviewed the FAQ document and answered questions regarding data accessibility and distribution. Ms. Feldman addressed a question regarding the data management vendor by stating that although the vendor was not a HIPAA covered entity or business associate, the same obligations and responsibilities, with respect to maintaining the privacy and security of all data received from submitters, could be inserted into the contract. Mr. Iacobellis provided context to a second question by Ms. Hyman by offering the example of the APCD acting as a business associate of the ACO, in which case, the ACO came to the APCD to work with data for research that aligned with APCD goals, versus a direct data request from the ACO. Ms. Feldman stated that the example would potentially be allowed in some instances, but the ACO would want to voluntarily fill that role. Mr. Iacobellis suggested that the APCD was not precluded to becoming a business associate of a HIPAA covered entity and Ms. Feldman confirmed this statement was true. Mr. Katz asked that Ms. Feldman confirm that the APCD was not able to give any identifiable data, but was allowed to analyze data on behalf of a requesting entity. Ms. Feldman stated that this statute circled back to Connecticut General Statute section 38A-1090 subsection (B)(2), which included the data deidentification requirement and noted that both the exchange and analytics were bound by the bill. Ms. Shipley requested information of the reason the exchange was requested identifiable data, and Mr. Ahmed replied by stating that analytics would synthesize data, which may require identifiable elements for tracking purposes, on behalf of the exchange to track healthcare trends and utilization. Mr. Blundo commented the information was a crucial component in creating patient identifiers. Mr. Iacobellis stated he was concerned that current language allowed for the exchange to perform the research with data containing identifiers. Mr. Blundo confirmed that it was common practice for vendors to offer the services to remove identifiers and replace them with de-identified identifiers. Mary Taylor offered in response a constructive overview of the approach taken by other states to encrypt identifiable information to allow a researcher to follow an unidentifiable person through health care provider and payer service. Mr. Ahmed added that limited data sets could contain state and county level data, which could be incorporated into data received by a requesting entity on a case-by-case basis. Mr. Ahmed continued comment on overarching legal parameters, which restricted the APCD to provide solely deidentified data and then suggested that legal parameters be deliberated by the subcommittee before the next legislative session.

Dr. Scalettar articulated the goal of the FAQ discussion, which was to enhance subcommittee comprehension of legal allowances and restrictions and to begin brainstorming and redacting legal terminology to better suit the needs of stakeholders. Mr. Katz remarked that Access Health Analytics could act as an agent by analyzing data on behalf of other agencies, and Mr. Ahmed indicated that the analytics team would provide analytic service by way of Enclave Modeling and analytic expertise.

Mr. Roberts continued to discuss the FAQ document. Mr. Roberts addressed the fourth question, which applied to the state laws concerning APCD data collection and maintenance, by explaining that the state data breach law, 36(A)-701(B) was the only law identified with relevance to this topic. Mr. Roberts stated that a security breach in the context of this law was defined as any unauthorized access or acquisition of personal information. Ms. Rexford asked whether the APCD could fine the vendor if a breach occurred in deidentification. Mr. Roberts provided that typically the vendor was responsible for reimbursing cost caused by or arising from action of the vendor. Ms. Taylor requested information of state or federal laws that would impact the ability of a payer to give the APCD data such as behavioral health, sensitive diagnosis, or substance abuse information. Mr. Roberts replied by indicating that the state legislation for the APCD did not address laws that may apply to the payers and their distribution of this data. Mr. Roberts remarked that payers were held accountable to laws that would restrict the content of data submissions beyond those promulgated by APCD legislation. Ms. Taylor continued to comment on a concern regarding the high expense of APCD payer submissions. Dr. Scalettar thanked Ms. Taylor for her support during this iterative learning process and requested the subcommittee to reach out to stakeholders and payers to learn about their experiences with APCD submissions in other states and requested that the legal consultants look into regulations that may restrict APCD data collection.

Mr. Roberts proceeded to review items five through seven on the FAQ document. Ms. Shipley posed a question regarding the seventh item, which concerned whether the state of Connecticut would own the data and Mr. Roberts replied that Access Health would own the data due to the quasi-agency status of Access Health Analytics. Ms. Shipley iterated her concern that at least some of the data belonged to the state by definition of quasi and opined that the topic be tabled for investigation and future deliberation to come to a conclusion on the data ownership issue. Mr. Katz requested that the subcommittee consider how the APCD would handle a payer pulling out of the APCD if the opt-out provision was passed in the future and determine whether an opt-out would require their information to be removed from the database. Ms. Feldman clarified that the data would presumably not be given back to the payer and if this statement was not true then it would be dealt with on a legislative level. Mr. Katz posed a question to the eighth FAQ item regarding whether a state agency or APCD would own data upon its disclosure. Mr. Roberts replied that ownership would depend on whether specific procedures surrounding the data use agreement (DUA) required the agency to return or destroy the data following a given duration. Ms. Feldman indicated this policy would be set forth through a DUA, which would be established by the subcommittee. Mr. Rutchick raised the concern that the term shall or may seemed to be used incorrectly in the statute language. Ms. Hyman added that the term shall appeared to require the disclosure of data for any request that paralleled any one category in the APCD mission. Mr. Roberts responded by stating that the shall versus may issues, including those related to shall and may inconsistencies in language, were in the process of being investigated in the context of a DUA. Ms. Feldman recommended that the language related to shall and may be refined at the subsequent meeting. Mr. Ahmed indicated that shall was presently in the bill language and urged that a review committee process, similar in nature to that of the IRB, be considered for implementation to ensure appropriate disclosure of data. Discussion surrounding the challenge of shall versus may ensued.

Ms. Feldman reviewed the ninth item related to health care cost and care utilization. Mr. Iacobellis called attention to the term cost, noted that this term referred to the payer, and stated that payment was the appropriate term due to differences in their meaning, especially with the potential addition of Medicaid as a submitter. Ms. Feldman stated that altering the term cost to payment may be a beneficial revision.

Ms. Feldman closed the FAQ discussion by briefly reviewing the tenth and eleventh items on the document. Ms. Rexford suggested that the subcommittee diligently work toward transparency and buy-in during the internal review processes. Mr. Salner clarified that the internal processes would be developed through collaboration between this subcommittee, the Policy and Procedures Enhancement Subcommittee, and the APCD Advisory Group. Mr. Ahmed stated that the protocol, or scaffolding, in which the data requests would be reviewed would be compensated by requiring a data review committee to mitigate risk. Ms. Feldman addressed concerns raised by the subcommittee regarding subjective influences impinging on the integrity of an objective review process by reiterating that a DUA would contain the proper language and restrictions to relieve the challenges of deciding if and how the data would be used. Mr. Roberts referred to the limiting restrictions attributed by 514 for the purpose of highlighting that data requestors would only be able to receive deidentified data. Mr. Katz referred to

the tenth item and asked the question of whether consumer information would be available on an aggregate level, yet be specific to a given zip code. Mr. Salner, in response to the question by Mr. Katz, confirmed that aggregate data would be available, but did not state that it would definitely be available by zip code. Ms. Feldman stated that information not under the umbrella of individually identifiable health care information would not necessarily be subject to the deidentification requirement.

Dr. Scalettar addressed delays in the timeline to highlight that data would not be available for release as soon as anticipated to stakeholders. Mr. Ahmed indicated that the contract with the vendor would be prepared in the next month, data was expected to be received starting in May, and permission had been requested to start reporting in the fourth quarter of the year. Mr. Rutchick questioned the requirements for the vendor contract and Mr. Salner replied that a selection of federal and state requirements would be relevant in the process of vendor contract development.

VI. Initial DUA Research Findings and Best Practices

Mr. Ahmed, Mr. Blundo, and Christen Orticari reported on slides five through 15 to provide information on terminology and current APCD data review and release policies and procedures. Mr. Ahmed stated the CMS definitions for deidentified data, limited data set, data security levels, introduced the topic of data use agreements, and discussed their implementation in Massachusetts. Ms. Orticari provided an aggregate summary of data review committee (DRC) practices in Massachusetts and Colorado. The DRC could be viewed as a 'kill-switch' for the APCD administrator to mitigate risk.

Mr. Blundo presented a case study of the data review, release, and use agreement procedures and materials developed by Colorado. Mr. Katz requested clarification regarding whether Colorado commenced their DRC and DUA practice following their transition from quasi to not-for-profit. Mr. Blundo indicated that the transition occurred in 2011 and their APCD began receiving data in 2012, which pointed to their status as not-for-profit during DRC and DUA implementation. Joshua Wojcik remarked that the Colorado data review and release committee appeared to have a transparent process and requested clarification regarding whether there were checks and balances in place to handle a case in which the APCD Administrator decided to go against the committee recommendation. Mr. Blundo indicated that the topic would be tabled to permit time for researching an appeal process and the topic would be discussed at the next meeting. Ms. Shipley requested information on cost estimates for data requests. Cost varied by state and often, the rates were set to cover the procurement of data for a requestor. He suggested that the subject be further researched and discussed at the next meeting.

Damian Fontanella asked the location for data storage. Mr. Blundo indicated that Access Health Analytics was in the process of determining whether data would be stored according to the data enclave model in which data would be stored internally or sent via a feed of information. Mr. Blundo stated that this would be a topic to be discussed in future subcommittee meetings.

VII. Next Steps

Dr. Scalettar reminded the subcommittee the next APCD Advisory Group meeting would be held from 9:00 a.m. to 11:00 a.m. on April 10, 2014. Dr. Scalettar restated that all discussions of the subcommittee were iterative and encouraged the continuation of collaborative discussion throughout all developments taken on by the subcommittee.

VIII. Future Meetings

To be determined.

IX. Adjournment

Dr. Scalettar entertained a motion to adjourn the meeting. Motion seconded by Mr. Katz and Ms. Hyman, and passed unanimously. The meeting was adjourned at 3:25 p.m.