Minutes

Delaware Health Care Claims Database (HCCD)
Access Committee

Monday, July 8, 2019
DHIN Office: 107 Wolf Creek Blvd., Suite 2, Dover, DE 19901
3:00 p.m. to 5:00 p.m.

Attendance: See Attendance List end of Minutes

Meeting Objectives:

- Vote on HCCD Data Request – CDC PFAS Study
- Update on Interagency Agreement between DHIN and Collaborating State Agencies

Agenda Item	Meeting Notes
1. Call to Order and Welcome a. Introductions b. Quorum	Meredith Tweedy resigned from the committee. Committee motioned, and approved that Jan Lee chair today's meeting. Jan Lee convened the meeting in Meredith's absence. Per State regulation, the DHIN Board will appoint the Committee's new Chairperson. a. Guests were introduced: i. Suzanne Condon of the CDC ii. Gonza Namulanda of the CDC b. Quorum was achieved – 6 Committee members were present. Please see attendance end of Minutes.
2. Approval of March 2019 Minutes	Corrections were offered related to the attendance list. Notably, Jill Hutt was not absent and was in attendance on the conference line; "Aetna" will be corrected to Karen Kane. Motion to accept with the 2 corrections was accepted. March 11 minutes will be posted to the public website.
3. Review Application #LD2 – CDC PFAS Study	Suzanne Condon provided overview of the CDC study and request for data. Historically, getting access to data to study environmental concerns have been problematic. This opportunity with claims data reduces this burden. In 2016, EPA found levels of PFAS across the US to be far in excess of EPA acceptable levels. Specifically, two communities in Delaware were impacted: New Castle City and Blades. CDC would like to look at health outcomes to determine if we can see the impact of PFAS in these two communities. CDC would utilize the claims data to study the frequency of certain diagnoses in the communities of interest, as compared to the frequency of these diagnoses in a control arm. This study will also determine whether claims data will be appropriate for CDC studies. Data collection are costly and difficult to attain. A study of Leukemia in Massachusetts was referenced to demonstrate the value of data and its sensitivity for analysis of exposure and causation. For purposes of this PFAS study, CDC will provide the geographic descriptors for which the HCCD would match and provide data. The study does not need identified data. The study does not need cost data or provider data, but does need outcomes, diagnoses, and test data. The CDC has contracted with Guidehouse to manage their studies across the country. Guidehouse will finance the study, but will not have access to the data. Only six CDC staff will be associated, and have access to, HCCD data
4. Public Comment	No comments from any reporting entities were received. No comments from the public were received.

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5. Discussion in accordance with the Decision Rubric	Consistency with the statutory purpose: Triple Aim, Improve health and Effectively manage the risk of a population. • The findings are expected to be published in a peer reviewed journal such as Environmental Health Perspectives Journal, or Morbidity and Mortality Weekly Report (MMWR) Journal. All work will be reviewed by the HCCD Committee prior to publishing any data. • Study is in Delaware. Study work will continue through August 2020. Some outcomes may not be available for 4-5 years, but preliminary reports may be available • The study conforms to statement 6 of the DOJ – Statement 6 is not relevant because there are no cost data being requested. • Study is requesting Pharmacy and Medical Claims data 2013-2018. • The study elements include the enterprise ID, gender, five-year age bands, 5 digit zip code or census tracts. • To assist with outcomes analyses, clinical data may be needed. DHIN is seeking approval from clinical data senders to share this data with the CDC in the future. This will also assist to enrich the claims person demographics such as race and ethnicity from the clinical data. • CDC may seek to link/compare claims data with clinical data in the future. Comparing/contrasting value of claims data vs clinical data is also part of the study. • Additional Questions: o Is it correct to say that Race and ethnicity is presumed to be relevant to some of these conditions? Yes o Is it correct to say that the Claim number and claim version number will be used to control for uniqueness of the claim? Yes o When will the CDC know more about what the control group will be, and when would this be brought back to this Committee? The data requested of the control group will be the similar data elements as what is chosen today. When this will be needed is unknown as yet. o There may be a need to collapse age groups for HIPAA protections. CDC is very familiar with CMS self suppression rules and will adhere to them. o Regarding the control group: In the analyses, would you be identifying the sources of water in the control group? Yes o The law about sharing data of fewer than 10 observations. Data can be shared with requestors, but it cannot be re-disclosed without omitting the groups with less than 10 observations o Are all providers in Delaware required to use EHR's? No, but 90% do. DHIN is in a fortunate position to know who does and who does not utilize EHR's o Does it matter if the claim is from an EHR or not? No, CDC is looking at numbers of events. Do not care who provided the service, or how much it cost. o DHIN has care summary data from about 115 practices. The agreements with these practices allow DHIN to utilize these clinical data for de-identified research. o With the statistical significance for MMWR, does this impact super funding? CDC does not get involved with this aspect or follow-up to this work. This study is to determine whether or not the people exposed to the elements have a greater risk than those who were not exposed. CDC will be managing an ecologic design for the study. • Data Security Management review o Data transfer storage and access. 4 storage mechanisms listed. Other mechanisms are not used. • Qualifications of Individuals as responsible stewards of the data. o No questions

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6. 5. HCCD Interagency Agreement Update	• The SEBC interagency agreement is completed. • DMMA and Division of Public Health agreements have been signed by DHIN and are awaiting signature by DHSS. • OMB draft is available. There does not seem to be strong interest from the OMB. • Homeland Security Agency agreement – Traumaitc Brain Injury has a bill that was passed that allows the Brain Injury Committee of the State Council for Persons with Disabilities (SCPD) to receive HCCD data as a state agency.
7. Public comments	Questions/comments: • Since this is investigating a public water supply: How do we manage the public and social media? The PFAS concern within the water supply has had multiple news articles and has already been published in Delaware Online. DHIN will be mindful of the public's perspective for its communications. • It is encouraging to see these data used for this type of project.
8. Decision and Next Steps	**Decision**: Approve the CDC PFAS Study - 6, approve with conditions 0, Deny – 0 **Next Steps** 1. Scott Perkins will work with CDC and Guidehouse for the Data Use agreement 2. Terri Lynn Palmer will work with the CDC data work group for business requirements of data transfer and the details of the data extract. 3. The CDC application will be posted to the public website. 4. Next meeting is scheduled for Aug 5. 5. Replacement for Meredith will come from the DHIN Board of Directors. 6. The CDC will provide study results to the Committee prior to disclosure
9. Adjournment	Next meeting Scheduled for Aug 5 – pending applications to review. Adjourned at 4:19pm

Attendance July 8, 2019:

Committee Member	*Present*	Conference line	Absent
Jill Hutt	X		
Bernadette Inskeep	X		
Karen Kane	X		
Jonathan Kaufmann	X		
Stephen Lawless		X	
Jan Lee *(Acting Chair)*	X		
Kathleen Matt			X
Faith Rentz			X
James Spellman		X	
Liz Staber	X		
Meredith Stewart-Tweedie (Chairperson) *RESIGNED 7//2019*			X

DHIN	*Present*	Conference line	Absent
Krista Foutrakis		X	
Sachin Gavali		X	
TerriLynn Palmer		X	
Scott Perkins	X		
Jeff Reger		X	
Stacey Schiller	X		
Michael Sims		X	
Pier Straws	X		
Tanya Bernstein – Facilitator	X		
Linda Green		X	

Guests	*Present*	Conference line	Absent
Gonza Namulanda		X	
Suzanne Condon		X	
Donna Salt	X		