Meeting Minutes August 17, 2017 South Carolina Data Oversight Council Meeting

DOC Members Present

<u>Guest</u> Dr. Daniela Nitcheva, SC DHEC

Ms. Andrea Bickley, SCDHHS *via phone* Dr. Aunyika Moonan, SCHA Mr. Brandt Smith, SCMA *via phone* Mr. Jay Wolfe, Governor's Office Dr. Shae Sutton, SC DHEC

RFA Staff Present

Dianne Davis Sandra Kelly Sarah Crawford

The August 17, 2017 Data Oversight Council (DOC) meeting was called to order by Ms. Sarah Crawford at 3:05 p.m. Introductions were initiated by Ms. Crawford. She then presented the minutes from the July 11, 2017 DOC meeting. Dr. Aunyika Moonan motioned that the minutes be approved. Mr. Jay Wolfe seconded the motion. The July 11, 2017 meeting minutes were approved unanimously.

The first application for the release of restricted data, submitted by Ana Lòpez-DeFede, Research Professor and Director; Institute for Families in Society, University of South Carolina was titled "Evaluation and Reporting of Maternal and Infant Quality Improvement Metrics for the SC Birth Outcomes Initiative". This study will use RFA inpatient hospital data, Medicaid Data and SC DHEC Vital Records data to provide data outcomes for the South Carolina Birth Outcomes Initiative (SC BOI). Dr. Moonan motioned to approve this request. Dr. Sutton seconded the motion. The motion to approve passed unanimously.

The second application for the release of restricted data also submitted by Ana Lòpez-DeFede, Research Professor and Director; Institute for Families in Society, University of South Carolina was titled "Healthy Outcomes Project (HOP) for Uninsured". This study will use RFA inpatient hospital and emergency department data to address the Healthy Outcomes Project requirements for an outcome evaluation and cost analysis. Dr. Moonan motioned to approve this request. Mr. Wolfe seconded the motion. The motion to approve passed unanimously. The third application for the release of restricted data, submitted by Carol Stone, Director of the Bureau of Health Improvement and Equity with the SC Department of Health and Environmental Control, was titled "Chronic Disease, Injury and Maternal and Child Health Surveillance". The purpose of this data request is to conduct public health surveillance activities for chronic disease, injury and maternal and child health issues for the state of South Carolina. There were several concerns expressed by the council: the size of the cohort, the number of restricted data elements requested and the ambiguity of the surveillance activities that are being investigated. Ms. Bickley motioned to Table this request. Mr. Wolfe seconded the motion. The motion to Table the request was unanimous based on the following concerns:

- 1. The Council felt that the records should be restricted to specific diagnoses.
- The Council would also like you to revise the list of restricted data elements to the following:
 - a. RFA will provide age in years or months for those under 1
 - b. Unique Patient Number RFA assigned
 - c. Patient Zip Code
- If additional restricted elements are needed, supplementary justification will need to be provided.
- Also, the Council would like more information on the surveillance activities for which this data will be used.

The fourth application for the release of restricted data, submitted by John Pearce, PhD, Assistant Professor, Medical University of South Carolina, was titled "A study of air pollution mixtures and morbidity in South Carolina". This request was originally approved at the August 20, 2015 DOC meeting. An amended request to receive Census Block/Tract was tabled in the May 18, 2017 DOC meeting, pending additional feedback from the researcher on geography level being requested. The researcher further amended this request to focus on asthma-related health conditions. By focusing on a specific condition, the researcher limits the data they will receive in order to have a proof of concept for their analysis. The Council was still concerned about providing data at this level of geography. Ms. Davis, with RFA, provided a quick look at number of asthma related conditions, comparing tract and zip codes, for 2009 and 2010. In comparing the number of zip codes and tracts that have less than 5 discharges for an asthma related condition; there were roughly 65% of the zip codes versus around 45% for the census tracts. With this additional information, Dr. Moonan motioned to approve this request. Ms. Bickley seconded the motion. The motion to approve passed unanimously.

The fifth application for the release of restricted data, submitted by Julie Kanter, MD, Director of Sickle Cell Disease Research, Medical University of South Carolina, was titled "Predictors of Acute Care Utilization in Sickle Cell Disease". This request was tabled at the February 16, 2017 DOC meeting pending some clarification of elements being requested and the status of the IRB. The request was approved as an aggregate request in the May 18, 2017 DOC meeting. After a discussion between RFA and the researcher it was determined that not all of the appropriate documents were sent for the last DOC meeting. The researcher resubmitted the request with the updated protocol and patient consent letter. There was some concern regarding RFA providing the patient information from other hospitals in the area without their knowing. Dr. Sutton motioned to approve this request with the condition that the researcher obtain Hospital Consent letters from other hospitals in the area. Dr. Moonan seconded the motion. The motion to approve with the added condition of the researcher obtaining consent letters from the other hospitals in the area passed unanimously. **Follow-up:** RFA had a call with the researcher

and Dr. Kanter has decided not to request HID at this point in time. If it is needed in the future, she will obtain consent letters from associated hospitals.

The sixth application for the release of restricted data, submitted by Kit Simpson, Professor, Medical University of South Carolina, was titled "SC Prescription Drug Overdose Prevention for States". The requested data will be used to assess the expected and unexpected consequences of requirements for monitoring the opioid prescriptions. Mr. Wolfe motioned to approve this request. Dr. Sutton seconded the motion. The motion to approve passed unanimously.

The seventh application for the release of restricted data, submitted by Matthew J. Notowidigdo, Associate Professor of Economics, Northwestern University, was titled "Retrospective Evaluation of the Impact of MCO Assignment". This study will use All Payor Hospital data, Medicaid data and DHEC Vital Records data housed at RFA. SC Department of Health and Human Services is a key partner in this research request, so the Medicaid portion has already been approved. The DHEC request is still pending. Upon review of the application, there was some concern over the need to provide actual dates, zip code and Hospital ID. The following changes were suggested for the researcher's application:

- Select only one hospital characteristic in the Inpatient Facility characteristics.
- Receive a distance calculation from RFA in lieu of getting zip code and HID.
- Receive a flag indicating coverage by MCO at time of hospitalization and month / year for dates instead of receiving actual dates.

Dr. Moonan motioned to approve this request with the specified caveats. Mr. Wolfe seconded the motion. The motion to approve with the specified caveats passed unanimously.

The eighth application for the release of restricted data, submitted by Rie Sakai-Bizmark, MD, Assistant Professor LA BioMed at Harbor-UCLA Medical Center and the David Geffen School of Medicine at UCLA, was titled "Impact of Pulse Oximetry Screening". The request was and amended request to an application that was approved in the July 11, 2017 DOC meeting. This amendment was requesting the addition of an encrypted Hospital ID. Mr. Wolfed motioned to approve this request. Dr. Sutton seconded the motion. The motion to approve passed unanimously.

The final application for the release of restricted data, submitted by Scott A. Lorch, MD, Associate Professor of Pediatrics, Perelman School of Medicine, University of Pennsylvania, was titled "Effect of Changing NICU Patient Volumes and Levels of Care on Neonatal Outcomes". This study proposes to link All Payor Hospital data with DHEC Vital Records data to examine the changes of NICU patient volume and levels of care on Neonatal Outcomes. DHEC is still reviewing this request. This study had two Aims: Aim one looked at NICU volume and levels of care and Aim two was a general look at the interaction between initial outcomes and how changes in volume and level of care affect outcomes for all births. The council felt that the second Aim was not as clearly defined as Aim one focusing on NICU. With that, the council felt that these should be broken up into two separate requests and provided the following suggestions for the researcher.

- For Aim 1:
 - · Focus the cohort on just NICU
 - · Pair down the variables requested, focusing on minimum necessary.
 - Provide clarification and justification for needing 20 years of data.
 - Inform them of the existing Perinatal Regions already defined in SC by DHEC.
- For Aim 2:

This needs more details and justifications.

Due to these concerns Dr. Sutton motioned to Table this request. Dr. Moonan seconded that motion. The motion to Table was unanimous based on these concerns.

Under the topic of General Discussion, the DOC was made aware of a pending subpoena from the Federal Trade Commission for an Anti-Trust Investigation. Based on previous discussions of subpoena the DOC approved for RFA to comply with subpoena.

Dr. Shae Sutton announced to the Council that she was leaving her position and the SC Department of Health and Environmental Control at the end of the month and would no longer be serving on the DOC. We are awaiting the appointment of a new member from DHEC.

This concluded the August 17, 2017 DOC Meeting. The next scheduled DOC meeting is November 16, 2017 at 3:00 p.m. The meeting was adjourned at 4:40 p.m. by Ms. Crawford.