

GREEN MOUNTAIN CARE BOARD
Data Governance Council
Friday, September 6, 2019, 1:00 pm

Attendance (Voting Members)

Susan Barrett, Council Chair and Executive Director, GMCB
Tom Pelham, Board Member, GMCB
Lauri Scharf, Manager of Informatics, Bi-State Primary Care Association
Andrew Laing, Chief Data Officer, Agency of Digital Services
Cathy Fulton, Executive Director, VPQHC
Mary Kate Mohlman, Health Services Researcher, Blueprint for Health
Alena Berube, Director of Value Based Programs & ACO Regulation, GMCB (after voted in as new member; see below.)

Others Present

Kate O'Neill, Chief Data Steward, GMCB
Lynn Combs, Associate General Counsel, GMCB
Sarah Lindberg, Health Services Researcher, GMCB
Lindsay Kill, Health Care Data Analyst, GMCB
Sean Judge, VAHHS-NSO
Adam Atherly, University of Vermont Larner College of Medicine
Caitlyn Daymon, University of Vermont Larner College of Medicine

Call to Order, Chair's Report

Susan Barrett called the meeting to order at approximately 1:00 pm. Susan announced the GMCB recently approved a Data Use Agreement (DUA) with the Office of the Vermont State Auditor. The upcoming 9/25/2019 Board meeting will focus on VHCURES in Action. At the federal level, U.S. Senate bill S.1895 passed the Health, Education, Labor, and Pensions (HELP) committee, and may be on the full senate calendar in September 2019. The October 1, 2019 DGC meeting needs to be moved, and October 25 is the proposed new date.

June Meeting Minutes

The Council voted (6-0) to approve the minutes from June 4, 2019.

Council Member Change Recommendation

Susan recommended Alena Berube, on staff at the GMCB as Director of Value Based Programs & ACO Regulation, to fill the vacant seat on the DGC. Susan summarized Alena's resume. Susan made motion to appoint Alena Berube to the DGC seat vacated by Pat Jones, and Cathy Fulton seconded. No discussion. Members voted 6-0 to approve the motion.

Update on Technical Assistance to Vermont

Mary Kate Mohlman provided an update on technical assistance that Vermont is engaging in with the National Governor's Association (NGA) and Actionable Intelligence for Social Policy (AISP) to consider opportunities for data sharing and integration. Andrew Laing spoke about the business need providing the motivation for better integration of data assets and that the team of State agency representatives is interested in a framework for Vermont.

VUHDDS Overview

Kate O'Neill introduced the presentation on the Vermont Uniform Hospital Discharge Data System (VUHDDS). The GMCB is the steward of VUHDDS, the Vermont Association of Hospitals and Health Systems - Network Services Organization (VAHHS-NSO) is the data collection and consolidation vendor, and the Vermont Department of Health (VDH) manages the data set for analysis and release. Sarah Lindberg reviewed the history of VUHDDS. Data come from the 14 Vermont hospitals and historically,

also neighboring states for VT residents (NH, NY, MA), and we are actively working with these states to restore current access. We recently added Brattleboro Retreat discharge data to the data set, and we are hopeful that soon we will be adding Vermont Psychiatric Care Hospital and White River Junctions Veteran's Association Medical Center discharge data, as well.

Sean Judge, VAHHS-NSO's Director of Health Care Data Services, presented on the data collection process, data flow, and security protocols. The Council discussed ambulatory surgery center data and data that follow patients across hospitals. Sarah spoke about the VUHDDS public use files and presented the VUHDDS data fields availability chart, asking for Council input on structuring the different levels of release. The Council suggested that availability of elements should be based on the role of an analyst, versus the organization for which they work. Kate explained that there is existing policy guidance for VUHDDS which GMCB still used to govern access, but that it was published in 2002 by BISHCA and under the upcoming process for Rule revision this policy may be replaced. Susan asked when the chart was last updated and Kate said that this is an uncommon occurrence, but we are contemplating changes to the availability of elements to support current VDH needs, particularly to support their tracking of progress on priority initiatives.

VHCURES Data Linkage Request Review

Kate reviewed the UVM College of Medicine request to link VHCURES data with the Vermont Cancer Registry and create a new research data base. The Vermont Cancer Registry has approved the request, and AHS IRB is determining whether full IRB review for approval is needed. Katelyn Damon and Adam Atherly from UVM College of Medicine answered questions from the Council about their research and proposed linkage project, which came from the research interest of a Radiation Oncologist who observed that patients from rural areas with lung cancer were presenting at a later stage, and commonly at a stage of lung cancer that is untreatable. There are limitations in each data set, but if linked, they could get a better longitudinal view of diagnosis and treatment. The goal is to pull ten years of data for a look back and to have a snapshot of those ten years for research, but there will not be a refresh of the database with future data. There was discussion on guardrails for reidentification, and the process of approval. At minimum the VHCURES DUA data protection requirements must be adhered to and there may be additional requirements from the VDH Cancer Registry for the combined data set. There would be no contemplation of anyone else gaining access to this data set. At minimum, all VHCURES data use agreement protections will apply to the creation of this new data set, and this will be explicitly stated in the approval of any linkage request. As part of the approval process for linkage, the GMCB will remind applicants of these limitations and of the protections agreed to in the underlying DUA.

Mary Kate Mohlman made a motion that the Council approve UVM COM's request for data linkage subject to conditions, specifically, that, 1.) after the proposed five year term provided in this specific data linkage request have expired that the Council revisit the data linkage to decide whether or not it would be appropriate to continue, that, 2.) the minimum standards that govern any and all use of this combined data set are those set forth in the VHCURES Data Use Agreement and data governance Rules, and that, 3.) the approval is subject to and inclusive of a final recommendation and decision from the AHS Institutional Review Board and any issues that that may raise that the Council would need to discuss further. Cathy seconded the motion. No further discussion. Council members voted to approve the motion (7-0).

The Council noted that any use of this combined data set for research that is not described in this application would need prior approval by this Council. Susan agreed to send a letter to the applicants indicating approval of this application subject to the above conditions.

Public Comment: None.

New Business: None.

Adjourn: The Council voted (7-0) to adjourn at approximately 2:57 pm.