

GREEN MOUNTAIN CARE BOARD
Data Governance Council
June 2, 2020 2:00 pm, via Skype

Attendance (Voting Members)

Susan Barrett, Council Chair and Executive Director, GMCB
Tom Pelham, Board Member, GMCB
Alena Berube, Director of Value Based Programs & ACO Regulation, GMCB
Lauri Scharf, Manager of Informatics, Bi-State Primary Care Association
Cathy Fulton, Executive Director, VPQHC
Mary Kate Mohlman, Health Services Researcher, Blueprint for Health
Absent: Helen Reid, VDH

Others Present

Kate O'Neill, Chief Data Steward, GMCB
Lynn Combs, Associate General Counsel, GMCB
Sarah Lindberg, Health Services Researcher, GMCB
Michael Barber, General Counsel, GMCB
Eric Schultheis, HCA
Michael Durkin, BCBSVT
Sean Judge, VAHHS-NSO
Jennifer Kaulius, UVMHC
Richard (Mort) Wasserman, University of Vermont Larner College of Medicine
Kathy Mahoney, Baystate Health, GMCB Advisory Committee member

Call to Order, Chair's Report

Susan called the meeting to order at 2:04 pm. Susan announced that GMCB staff is working remotely. Susan also shared that the recently approved VHCURES application for Archway Health was finalized; they now have a DUA with the GMCB and are working with GMCB's vendor for access to the data set.

Approve December Meeting Minutes

The Council voted (6-0) to approve the minutes from February 4, 2020.

Draft Data Linkage Policy

Lauri Scharf pointed out that the Policy draft doesn't define data linkage. Kate O'Neill said she would revise the current draft to include a definition. Mary Kate Mohlman asked about identity management particularly with linking multiple data sets, and in the case of multiple data sets would the requestor need separate approvals? Lynn Combs reminded the Council that a condition of data linkage approval is consent of all data owners. Kate shared that because of this, each linkage would need to be documented separately and that the current policy language would address that. Mary Kate would like some language to address the scenario of additional linkages in that all data owner would support additional linkage. Kate will revise the Policy to reflect this. Mary Kate asked about requiring a summary or progress report on data linkage projects. Kate shared that the principal investigator under the DUA files semi-annual progress reports and that would still hold, even with data-linked projects. Tom addressed the balance between keeping the ability for the state to benefit from research but not having it as an obligation or condition of release. Susan shared that we would want to balance the information we might receive with the

expectations under the DUA, but not as another requirement of a DUA. Sarah added that we strive to strike a balance with restrictions and requirements that still encourages usability of the data set. Council members provided some editing suggestions to the Policy format. Kate will update the language and will present a revised draft at the August meeting.

Public Comment

Mort Wasserman shared that from his standpoint, as someone who has used VHCURES for research, and has used linked data, data linkage means different things to different people, so it is critically important to define it in this Policy.

Allowable Release

Lynn presented an overview and update on the permissible releases of VHCURES and VUHDDS Data, including a walk-through of the governing Rules and Policies.

Kate presented an update on the recent changes to the data release application processes, including updating the VHCURES Limited Use Data Preliminary Request, and the creation of a State Agency DUA application process for VUHDDS to match the process we use for VHCURES.

Related to the State Agency broad-use DUA, Cathy Fulton wants to be sure that we still have tracking and accountability in place for use of data within divisions of state agencies. Kate said that we do track authorized individual users and have accountability measures in place, so we know who has access to the data, who is using it, and how it being used.

Public Comment

Mort Wasserman made a general comment that given the current turmoil in this country and increasing emphasis on health disparities, race and ethnicity data in VHCURES needs to be better. Currently, while collected by the insurer, there is a lot of missing data, is not of good quality, and it is not accessible for researchers using claims data to know self-designation of race. So, researchers are unable to find disparities. To what extent does the DGC or the GMCB itself help to encourage having such data in the data set? Sarah shared that while we haven't worked recently with insurers to triage this issue, it is our understanding that it is not a very reliable element from payers. However, we are about to kick-off a validation project with payers and providers and that can be one of the elements we can address. We can start by understanding the variation of that element among the different data sources and get a sense of the possible barriers to improvement. It is in VHCURES, but not well-populated today. Sarah asked if Mort could share any resources he has or knows of other states that have had better compliance with that field from payers. Mort said he'd share what he can find. Susan added that the Governor just recently established a racial equity task force and health is one of the key areas they are addressing. We can reach out to this task force for their help and involvement.

New Business

None.

Adjourn

The Council voted (6-0) to adjourn at approximately 3:32 pm.