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February 23, 2018

Green Mountain Care Board
3rd Floor City Center
89 Main Street
Montpelier, VT 05620

Re: Data Governance Council Charter

Dear Members of the Green Mountain Care Board,

Thank you for the opportunity to comment on the Data Governance Council's Charter (Charter). We have taken some time to review the document and we have some serious concerns.

As the document recognizes, the state of Vermont has given the Green Mountain Care Board (Board) stewardship over VHCURES (Vermont Health Care Uniform Reporting and Evaluation System) and VUHDDS (Vermont Uniform Hospital Discharge Data Set). The Board appears to have created the Data Governance Council to help ensure that the Board has an appropriate system for managing data set privacy and security, quality and utility, sustainability, and access. The Charter should outline the Council's role in achieving these goals.

In contrast, the Charter gives no clear role to the Council. Other than the Chair, the Charter describes the Council members as having voting power but provides no information on what decisions the Council is responsible for making, what decisions the Council must vote on, what decisions the Green Mountain Care Board must approve, and what decisions the Chair can make on his or her own. The Charter gives broad powers over data governance to the Chair of the Council. The Chair may appoint members of the council, make decisions on requests for use and disclosure of data, delegate work to staff, lead council meetings, and "facilitate the decision-making process of the Council." The role of the Chair is automatically filled by the Executive Director of the Green Mountain Care Board. Executive Directors of the Green Mountain Care Board will not necessarily have any expertise in data governance and will have many other responsibilities to attend to in addition to data stewardship.

We are sympathetic to the statements in the Charter that the Council should be "agile" and therefore the Charter should not be overly prescriptive. But giving a reasonable amount of definition to the Council's role is important for several reasons: 1) it will allow potential members to understand the role and level of commitment involved; 2) it will serve as a guidepost for current Council members and Board staff which will help ensure

that everyone has a common understanding of their basic role and what is expected of them; and 3) it will ensure a balance of power among the members of the Council and utilize their various skills and expertise.

In light of the import of the Board's role as health care data steward for the state of Vermont, we urge the Board to clearly define the role of the Council within the Charter, including what matters the Council will vote on. At a minimum,

- The Green Mountain Care Board should vote to establish what decisions on data use and disclosure must be deferred to the Board. Other decisions can be brought to the Board at the discretion of the Council or Chair.
- The Council should either vote directly on requests for use and disclosure of data, or vote to establish the standards and process the Chair and/or staff members will apply when they decide whether a data access request will be granted. If the Council chooses not to vote directly on the requests, it must be given the opportunity to review all decisions on data access requests.
- Any applicants for access to the data who are denied, should be given the option to appear before the Council or the Board for reconsideration.
- The Council should vote to establish the standards and process the Chair and/or staff members will apply when they prioritize the work backlog.
- The Council should vote on changes to membership. At least one Board member should be on the Council. If that is not currently possible, the Charter should at least leave that option open. The current draft does not list a voting member category that could apply to a Board member.
- Any significant changes or threats to the Board's data stewardship must be disclosed to the Council. The Council should have the power to vote to approve or reject the change or the solution to the threat. The Board can override these decisions if they choose. Examples of significant changes or threats to stewardship should include, but not be limited to, offering the data on a new platform, a breach in data security; and implementing or lifting a moratorium on the review of data use agreements.
- The Council should develop and vote on a list of work objectives, to be updated as needed, but no less than annually.
- As needed, the Board should decide any additional items that should require the Council's review and approval.

In addition to the points outlined above, the charter should state that considerations of data utility will focus on uses that help meet the Board's data governance duties listed in 18 V.S.A. §9410(a) and that serve the public good.

Thank you for taking the time to consider our comments on this issue.

Sincerely,

s\ Mike Fisher, Chief Health Care Advocate

s\ Kaili Kuiper, Staff Attorney