

Green Mountain Care Board

Data Governance Council

Data Stewardship Principles and Policies

Adopted the Board

January 8, 2015

Introduction

On September 4, 2014, the Green Mountain Care Board approved the development of a data governance program and the formation of the Council to implement the program. The data governance program is intended to provide a structured approach to the management of data resources at the GMCB. This program will focus on four key areas:

- **Data quality** - Establishing data stewardship to monitor the quality of VHCURES and other data resources.
- **Risk** - Ensuring best practices with regards to data privacy and security.
- **Finance** - Evaluating opportunities for VHCURES to optimize financial sustainability and revenue.
- **Data Release** - Supporting clear processes for the evaluation of data requests and the release of data to State and non-State research entities.

In order to guide the Council's decision making in these four key areas, the Council began its work by drafting data governance Principles and Policies. The Data Governance Council drafted seven principles and corresponding policies. Upon adoption by the board the Principles may be referenced and accompany any data governance related documents including the VHCURES rule, the Data Protection and Disclosure Guide, the Data Governance Council Charter, and the Data Submission Guide. Please note that while Principle 1 describes the privacy of Vermonters as the highest priority, the remaining principles are not presented in a rank order of importance.

Principle 1

The highest priority for GMCB data governance is the protection of individuals' privacy and their protected health information.

Policies

- 1.1 GMCB data release policies and procedures are designed to prevent direct disclosure or any derivation of the data that could result in the identification of individuals and their protected health information.
- 1.2 GMCB release of VHCURES data is limited to the use of the minimum necessary data required to support the goals and objectives approved under a data use agreement. No other uses of or access to data are permitted.
- 1.3 Matching of VHCURES data to other data sets will only be permitted if and to the extent it is approved under a data use agreement.
- 1.4 No person may use or access VHCURES data other than pursuant to an approved data use agreement.
- 1.5 Data requestors must demonstrate adequate procedures and protections for data privacy and security.
- 1.6 GMCB's policies and procedures for data release shall be published in the "GMCB Health Data Protection and Disclosure Guide".

Principle 2

GMCB data resources are used to support health and health services research that is non-proprietary, serves the public interest, and is applicable to large populations.

Policies

2.1 GMCB data release policies and procedures pertaining to the review of applications for data use agreements include criteria addressing:

- a) The competency and expertise of the researchers to conduct a proposed study;
- b) That the researchers provide a compelling argument regarding the objectives and significance of a proposed study;
- c) That the researchers provide a well-structured research protocol;
- d) That the study is not intended to support the creation of a proprietary, commercial product that the researchers intends to market for sales; and
- e) That the researcher provides information regarding the source of funding for the research and verifies the independence of the research organization.

Principle 3

The use of GMCB data resources will support the GMCB's mission and mandates for health care system regulation, innovation, and evaluation while protecting the proprietary information of insurers and providers.

Policies

- 3.1 GMCB data release policies and procedures align with the GMCB's responsibilities for data stewardship and support research in the public interest about the cost, use, and efficiency of health care services in a manner that does not violate federal antitrust provisions.

Principle 4

The GMCB data will be maintained in a transparent manner that achieves the highest possible quality.

Policies

- 4.1 Data quality will be monitored and continuously improved.
 - a) The Board will set standards for data submission quality. Data quality results will be regularly reviewed and quality monitoring processes will be updated as needed to continually improve data quality.
- 4.2 Data will be regularly validated.
 - a) Data submitters will be engaged to validate the data they have provided.
 - b) Data validation measures, if available, will be accessible by analysts.
- 4.3 Data cleaning techniques for VHCURES will be transparent.
- 4.4 Data cleaning and transformation standards for VHCURES will be clearly specified, and algorithms used to transform raw data will be made available.

Principle 5

GMCB data will support timely, consistent, and actionable analyses.

Policies

- 5.1 Data will be available for timely analysis.
 - a) Timeliness will be balanced against data quality.
 - b) Data must be of high quality to produce good, trusted results, but quality efforts cannot become so consuming as to prevent analytic work from going forward.
- 5.2 Data will support the Board's analytic priorities.
 - a) Quality improvement work will be guided by analytic needs.
- 5.3 Data will be managed in a format that will support both common analyses and ad hoc use.
 - a) Management of the data will align with Board priorities and will allow other types of analysis.
- 5.4 Databases will include common definitions to support consistent analyses.
 - a) Fields will be added to the analytic files to support work using areas where definitional difference may produce conflicting analysis.
 - b) Algorithms used in creating value-added fields will be made publicly available.

Principle 6

The GMCB will pursue the financial sustainability and accessibility of its data resources.

Policies

- 6.1 State Agencies will be allowed to use the data “at cost.”
 - a) Agencies will be charged for data access/use to cover the actual cost of maintaining VHCURES.
 - b) The Board will establish and report on and established costs an annual basis.
- 6.2 The Board reserves the right to charge fees for use of the data for general purpose research.
 - a) The GMCB may collect revenue from these uses beyond the actual costs of operating VHCURES to ensure that Vermonters benefit from the use of their data for general research.
- 6.3 The Board will limit the release of data, even when reimbursed, to uses that benefit the general public good.
 - a) The Board may bring in revenue from the use of VHCURES data, but the purpose of the data is still to serve the public good.
 - b) The benefit to Vermonters will be financial in cases where the public good element is not specific to Vermont.

Principle 7

GMCB will engage with stakeholders to optimize the value proposition of its data resources through changes in scope of data collection and accessibility.

Policies

7.1 Data submitters will have the opportunity to influence changes in technical specifications when proposed.

7.2 Proposals to change the scope or accessibility of data will consider feasibility, burden on data submitter, cost, and relevance of use case to research agenda, impact on data quality, privacy, anti-trust concerns, and general usefulness of the proposed change.

Document Revision History			
Version	Delivery Date	Author	Notes
1.0	October 16, 2014	Peter Alfrey, BerryDunn	For review by the GMCB Data Governance Council
1.1	November 4, 2014	David Regan, BerryDunn Stacey Murdock GMCB	Combined revisions from the 10/16 Data Governance Council meeting. Added Principle 7
1.2	January 8, 2015	Stacey Murdock GMCB	Removed Policy 6.2 (a). Board members voted unanimously to adopt this version of the document.