

POLICY

Policy Regarding Data Linkage GMCB Data Governance Council

Effective Date: August 14, 2020

A. Introduction

The Vermont legislature authorized the collection of eligibility and claims data for Vermont residents to enable the Green Mountain Care Board (GMCB) to carry out its statutory duties. Those duties include determining the capacity and distribution of existing resources; identifying health care needs and informing health care policy; evaluating the effectiveness of intervention programs on improving patient outcomes; comparing costs between various treatment settings and approaches; providing information to consumers and purchasers of health care; and improving the quality and affordability of patient health care and health care coverage (18 V.S.A. § 9410). The GMCB has the authority to make the Vermont Health Care Uniform Reporting System (VHCURES) and Vermont Uniform Hospital Discharge Data System (VUHDDS) data sets available to the extent permitted by the Health Information Portability and Accountability Act (HIPAA) and other pertinent state and federal laws and regulations and policies.

The GMCB chartered the Data Governance Council (DGC) to oversee the stewardship of VHCURES and VUHDDS including the development and revision of principles and policies to guide decisions on data use and disclosure. The DCG supports the GMCB decision-making process for applications requesting use, disclosure, and redisclosures of GMCB data assets.

For the purposes of this Policy, the Green Mountain Care Board defines data linkage as the merging of two or more unique data sets or files to connect common identifiers across the sets. Data linkages are carried out to improve the robustness of research data and to create more complete data sets. Linkage may be necessary in health services research to answer a specific research question. While the Authorized User (linkage requestor) would facilitate the data linkage, stewardship of the underlying data sets remains with the steward(s). This Policy does not address, nor will the GMCB contemplate, linking of data sets for the express purpose of creating a new, novel, or “master” database that would then be under the sole authority of the entity establishing the linked data set.

B. Policy

Through this policy the DGC shall support to the maximum feasible extent the fulfillment of the above statutory duties. The GMCB supports meaningful use of its rich data resources and understands that there are times when research and analyses require more robust data than can be obtained from an individual source. All data linkage projects utilizing GMCB’s data assets must be consistent with the DGC’s and GMCB’s existing principles and policies that guide data use and disclosure decisions and must be consistent with the GMCB’s legal authority. Therefore, GMCB allows linkage of its data assets with other sources of data within the following limitations of this Policy.



- The linkage must be necessary to conduct research that would otherwise not be reasonably practicable; and in considering data linkage approval, GMCB will strive to balance privacy and security risks with the potential consequences of not conducting research using proposed linked data.
- The linked data set must, at minimum, adhere to the protections and constraints of the underlying GMCB Data Use Agreement.
- The most restrictive limitations from each data set must be applied to the linkage agreement.
- The benefits to Vermonters that would be gained from the proposed linkage must be clear.
- The requestor's data management plans and research and reporting protocols must employ methodologies and strategies that minimize the risk of disclosureⁱ of personal identities outside of the linkage process, and prevent the disclosure of sensitive attributes of those people, such as medical diagnoses and treatment, to entities external to the research team.
- Any amendments to an approved data linkage, including linkages to additional data sets, need to be reviewed and approved prior to any amended activity.

C. Implementation

- In considering data linkage requests the GMCB will apply equivalent review protocols as established for GMCB's limited use research data set Data Use Agreement applications.
- The GMCB and data linkage applicants will secure approval from stewards of proposed linked data in the form of a Memorandum of Understanding (MOU), IRB approval, or other written agreement.
- GMCB reviews all requests—regardless of origin—to link GMCB data assets with other data sources.
- Review of proposed data linkage projects will include assessment of the following criteria:
 - purpose of linked data and outline of proposed procedures for data linkage
 - feasibility of data linkage
 - assessment of data quality of resulting linked data set, including whether research questions are answerable, the structure is satisfactory, and data are sufficiently robust to obtain the level of granularity necessary for analysis
 - legal and ethical limitations on uses of source data sets and linked data set
 - data security and data management
 - depth and breadth of privacy interests implicated by the request
 - qualifications and technical abilities of research team
 - ownership of and terms governing the relevant datasets
- The GMCB will post to its website all projects that include linkage of any GMCB data assets, including how linkages are conducted, and the benefits derived from them.

ⁱ HIPAA defines disclosure as: the release, transfer, provision of access to, or divulging in any other manner of information outside the entity holding the information.

Source: *HIPAA Administrative Simplification Regulation Text*; U.S. Department of Health and Human Services Office for Civil Rights; Department of Health and Human Services; P.12;

<https://www.hhs.gov/sites/default/files/ocr/privacy/hipaa/administrative/combined/hipaa-simplification-201303.pdf>