

**University of Rochester
Data Governance Committee**

Hub Management Policy

Policy No. 2.0

Created: November 8, 2017

Last Revised: November 7, 2018

Policy Owner: Population Health Data Group

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Purpose

This policy provides the requirements for management of the ROC Health Data website.

Scope

This policy governs all processes for management and use of the ROC Health Data Hub and its Hublets, operated by the CARES Engagement Network (formerly known as Community Commons).

Introduction

The ROC Health Data website (RocHealthData.org) was created in 2017 in response to a need for local, geographically specific health data. RocHealthData.org serves as a repository for Rochester area health care data. This repository, or Hub, is a web based portal which can be used to share data, reports, and mapped information relevant to the Rochester area. Users may also create maps from many publicly available data sources (including but not limited to ARQH, the CDC, the Census Department, CMS, BRFSS, and the Robert Wood Johnson Foundation). This portal is maintained by the organization CARES (<https://engagementnetwork.org/>), which is responsible for technical support.

Elements

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1. Definitions

- **CARES Engagement Network** – Engagement Networks are websites that house thousands of public data sets and tools that help users to geographically display data, create custom reports and export and share findings.
- **Hub** – A Hub is a custom tool within the Engagement Network where members can access and share personal data sets. This increases the availability of data at the sub-jurisdictional level and offers a platform for data sharing through the use of a Hub library.
- **Hublet** – A Hublet is a partitioned site or space within a Hub. All the functionality of the larger Hub is available in a Hublet, and Hublets are often designated as sites for small working groups. The Hublet members may choose whether to share its information and data with the larger Hub or keep their information private to only members of the Hublet. This type of partitioned site may be advantageous for a group needing to upload more than the allotted number of data sets in a given year, or would benefit from technical support directly from the Engagement Network.
- **RocHealthData.org** – a Hub created for the upstate NY area: the city of Rochester and the surrounding multi-county area. Data and maps are available for a wide variety of health indicators and social determinants of health.
- **Data Governance Committee** - The Data Governance Committee (DGC) is the policy making body for RocHealthData.org.

The DGC is made up of representatives from the University of Rochester (Center for Community Health and Prevention and the Clinical and Translational Science Institute). Common Ground Health, the Monroe County Department of Health, and the Greater Rochester Regional Health Information Organization (RHIO).

- **Roles within the Hub** – there are currently 3 levels of membership / data access available within the Hub: Member, Moderators (known within our particular Hub as Data Custodians), and Administrator. These levels are determined by CARES and are progressive, such that higher levels of access incur higher levels of responsibility (see page 3 for roles and responsibilities of each level).
- **Data** – Data uploaded to the Hub by data custodians must:
 - Not contain any personally identifiable information
 - Be able to be aggregated at a geographic level
 - Have at least 10 observations per geographic unit, unless these data are non-HIPAA data. This Non-HIPAA data could include locations of medical

practices, tobacco stores, or other publicly available data such as locations of criminal activity.

Data uploaded to the Hub can be made private (visible only to uploader), Hub-only (visible only to members of the Hub), or public (visible to anyone within the Commons).

- **Geographic unit** – the geographic area to which data pertain. The smallest permissible geographic unit to be uploaded to the Hub will be census tract.

2. Capabilities and Responsibilities

CAPABILITIES: what Hub participants **MAY** do:

ACTIVITY	ROLE		
	Member	Moderator (Data Custodian)	Administrator
Views all information in the Hub.	X	X	X
Uploads data to the Hub.		X	X
Designates the availability of uploaded data.		X	X
Downloads data from the Hub as well as from publicly available data sets.		X	X

RESPONSIBILITIES: what Hub participants **MUST** do:

ACTIVITY	ROLE		
	Member	Moderator (Data Custodian)	Administrator
Reviews and signs an attestation that they will abide by the rules established by the Engagement Network and this policy.	X	X	X
Completes fully the requested data information form within the Engagement Network as part of the upload process.		X	X

Contacts the owner of a Hub data set if the user plans to use any available downloaded information for a grant, publication, etc.	X	X	X
Agrees that their uploaded data may be viewed and downloaded by other members of the Hub.		X	X
Uploads no more than 12 data sets to the Hub per year. There is no limit on private uploads. Should a Moderator need this limit increased, discuss options with Administrator.		X	
Bears full responsibility for any and all questions that arise from others related to their data set.		X	
Manages all requests for Hub access and address any questions pertaining to the Hub.			X
Serves as the point of contact to the CARES Engagement Network support for Members and Moderators.			X
Grants permissions for levels of access (Members or Moderators) to the Hub.			X
Ensures that Moderators and Members comply with all responsibilities listed above.			X
Brings any other issues, as they arise, to the attention of the full DGC for discussion and resolution.			X

3. Process for Membership

A. To become a member

1. Visit RocHealthData.org and choose “Register” on the homepage.
2. Complete the registration form, including reading and agreeing to these terms of membership.
3. Access will be granted immediately upon completing the registration form.

B. To become a moderator (data custodian)

1. Send a request to become a moderator to RocHealthData@URMC.Rochester.edu

2. The moderator will receive email notification when their request has been approved.

C. To grant moderator status (data custodian)

1. Administrators will receive an email when a request is made.
2. Administrators ensure that members and moderators agree to the terms of membership.
3. The Engagement Network will send an email to verify membership status.
4. If Moderators compliance with stated data upload responsibilities is not fulfilled, changes to ensure compliance must be made within 5 business days. If the changes are not made, the Administrator will remove the data.
5. Administrators bear no responsibility for maintenance, updating, timeliness, accuracy or interpretation of data.

4. Creating New and Revising Existing Policy

Proposed revisions or new policies are brought to the Data Governance Committee once a year, or more often as necessary. Policy documents will be updated no more than once per year.

5. Governance of Hublets

Any member of RocHealthData.org may request access to their own Hublet. Hub Administrators can provide, upon request, more information about the creation and cost of a Hublet. Members who wish to create a Hublet are responsible for all financial obligations associated with creation and maintenance of a hublet.

Any group that creates a hublet must share their data governance policy with the ROC Health Data Data Governance Committee. This policy is a supplement to the requirements outlined in the Hub Management Policy. It may be a mirror of this policy, or include additional terms.