



This document provides an overview of the Carolina Cost and Quality Initiative (CCQI) and outlines the requirements of projects using CCQI. A project's principal investigator is responsible for ensuring all project personnel comply with the requirements outlined here.

### CCQI Overview

#### What is the Carolina Cost and Quality Initiative?

The Carolina Cost and Quality Initiative (CCQI) is a collaborative partnership between the Cecil G. Sheps Center for Health Services Research and owners of North Carolina healthcare services data to build, maintain, oversee, and promote the use of data for research. Research conducted as part of the CCQI typically focuses on the incidence and prevalence of disease in target populations, patterns of utilization and treatment, and cost of care in North Carolina. The overall objective is to improve the delivery and quality of care to North Carolina residents.

UNC-Chapel Hill, on behalf of CCQI, has established agreements with a variety of data owners to acquire and facilitate reuse of these data. These agreements with public and private partners allow CCQI to make the data available to UNC researchers by request. These data are owned by the various partners and are available through CCQI due to a mutually collaborative partnership between the data owners, CCQI, and its network of researchers.

#### How does the data request process work?

Researchers initiate the approval process by submitting a completed data request. The CCQI Oversight Committee reviews all data requests. The full approval process can take several months, depending on whether revisions are required. Once approved by the CCQI Oversight Committee, requests will be sent to review committees at the specific data owner. The entire review process is coordinated by the CCQI project manager. If your data request is approved, the Sheps(DATA)+ team will work with you to create a project-specific analytic data asset for each data source. Data preparation may take several months, depending on the number of pending requests, and will require funding Sheps(DATA)+ programmers.

#### Where do the data reside?

All CCQI data, *including HIPPA de-identified data extracts*, must remain on the Sheps Secure Research Computing Cluster (SRCC). The SRCC provides a storage and analytic environment that maintains the security and privacy of the data. The Sheps(DATA)+ team will help approved users with obtaining access to the SRCC. Fees for access to the Sheps computing environment will apply.

#### Who owns these data?

The data are not owned by the University of North Carolina, CCQI, or its researchers. The original data owners remain the only entities with ownership rights. As such, they may choose to terminate their data sharing agreements with CCQI at any time, at which point all research using that data must cease.

#### Who can access these data?

Almost all CCQI data are only available to permanent UNC employees and UNC students. This does not include affiliates or adjunct faculty except in rare circumstances and with specific data sources. If an approved researcher's status as permanent employee or student changes, they will no longer have access to CCQI data.



## Researcher Responsibilities

CCQI leadership and staff devote considerable time to maintaining our partnerships with data owners so that they continue to see the value in sharing their data. Researchers can help ensure that this partnership continues by adhering to the following requirements:

### Publications

- Include the following acknowledgement in all journal articles and abstracts using CCQI data:  
*The data analytic infrastructure used for this project was supported by the Carolina Cost and Quality Initiative (CCQI) and Sheps(DATA)+ at the Cecil G. Sheps Center for Health Services Research.*
- Submit all publications (e.g., journal articles or conference abstracts) to the CCQI project manager for review by the data owner, in accordance with the terms of your DUA. In some cases, submission may be required as many as 45 days in advance.
- For projects using BCBSNC data: Do not identify BCBSNC by name in any presentations or publications.

### Reporting

- Provide the following information by June 30 each year the DUA is active to the CCQI project manager:
  - Status of the research project (e.g., milestones met)
  - External awards supporting the work, including amount and funder
  - Dissemination efforts (e.g., presentations, publications, media coverage)
  - Graduate students supported (e.g., related dissertations, students funded)
  - Preliminary findings
- At the completion of the project, prepare a 1-2 page brief for public dissemination. The brief should highlight a finding of interest, focusing on the impact on the data owner and/or the public. CCQI staff will provide a template for the format of the brief and are available to consult on which findings to highlight. Findings should be presented visually such as in the form of bar charts or cross-tabulations, rather than a regression, and therefore should not overlap with academic publications. The specific form and content will vary; researchers are encouraged to discuss with the project manager well in advance.

### Data Governance and Information Security

- Promptly report changes in project staffing for individuals accessing the data.
- Comply with all Sheps SRCC User Agreements, including Rules of Behavior and Sanction Policy.
- Comply with UNC-Chapel Hill Information Security Policies and Procedures.

### General

**Comply with all policies and procedures outlined in this and any other data use agreements associated with specific data sources. If any policies in those agreements conflicts with the requirements outlined here, the most restrictive requirements will apply.**

## Acknowledgement

### Project Name

### Principal Investigator

I acknowledge the terms and conditions outlined above.

### CCQI Director or Representative

This project has been reviewed and approved by the CCQI Oversight Committee.