CCQI Overview and Data Use Acknowledgment

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 health care claims data to build, maintain, and oversee the use of data on North Carolina health care services and to promote the use of these data for research. Research conducted as part of the CCQI typically focuses on the incidence and prevalence of disease in insured 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.

CCQI has established data-sharing agreements with various data owners. These agreements with public and private partners allow CCQI to make claims and membership 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 owner and 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, Sheps Center programming staff will work with you to prepare your analytic dataset. Please note that data preparation may take several months, depending on the number of pending requests.

Where do the data reside?

All CCQI data, including analytic extracts, must remain on Sheps Center servers. Data users must conduct all analyses on Sheps Center servers. The Sheps Center's IT team will help approved users with setup and operation within the Sheps computing environment. Fees for accessing the Sheps computing environment may 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?

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

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What are my responsibilities as a researcher using this data?

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:

- 1. Follow the terms outlined in your data use agreement.
- 2. Include the following acknowledgement in all journal articles and abstracts using CCOI data:

The database infrastructure used for this project was supported by the Cecil G. Sheps Center for Health Services Research and the CER Strategic Initiative of UNC's Clinical and Translational Science Award (5-UL1-TR002489-05).

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3. 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.

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- 4. For projects using BCBSNC data: Do <u>not</u> identify BCBSNC by name in any presentations or publications.
- 5. 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)

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- Graduate students supported (e.g., related dissertations, students funded through grants received for this project)
- Preliminary findings
- 6. At the <u>completion</u> 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 crosstabulations, 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.

I acknowledge the terms and conditions outlined above: _		
-	(PI signature)	(date)