



Frequently Asked Questions (FAQ's): Use of ACHQC Registry Data by ACHQC Surgeons

How do I access ACHQC registry data?

You must complete an application (available at <https://www.achqc.org/data>) and sign a written Data Use Agreement with ACHQC along with its Standard Data Use Terms and Conditions.

Who signs the required Data Use Agreement and related standard terms?

You, as an individual surgeon, and ACHQC Executive Director will sign the Data Use Agreement and related standard terms. The agreement is personally between you and ACHQC and does not require that your institution approve or sign the agreement.

Are all ACHQC surgeons entitled to access the ACHQC Registry Data?

Only those ACHQC surgeons who are in Good Standing by being active, participating members of the ACHQC are entitled to have access to ACHQC Registry Data. To be in Good Standing, you must act in good faith and with reasonable diligence to contribute data to the ACHQC from your surgical hernia cases by entering at least 25 surgical cases with 30-day completed follow up and continuing the same rate of data entry for the 12-month period following the receipt of any ACHQC datasets.

Do I have to pay a fee to use ACHQC datasets?

No.

What is the data request process?

- Once a data request is received, it will go through a feasibility check.
- Once the request is approved by the Data Use and Publications committee, the QC lead analyst will reach out to the requesting surgeon to finalize data analysis plan
- After data analysis plan is agreed upon, the project will be assigned an analyst
- The analytic plan can be changed within reason, but requests to rerun or alter analyses with the sole purpose of obtaining a statistically significant result will not be accommodated
- During communication with our analytic team, if two email reminders for response are unanswered, your project will be taken out of the work queue and placed on hold. Restarting work on the project can take up to 4 weeks
- **Data requests with project deadlines must be submitted and their IRB approval letter provided at least 14 weeks in advance of the deadline**

Upon receipt, each project will be reviewed and must be approved by the ACHQC Publications and Data Use Committee. Once approved, each requestor is responsible for obtaining Institutional Review Board (IRB) approval for the specific project. Proof of IRB approval must be sent to the ACHQC at

aileen@achqc.org. Data reports will be provided under the terms of a written Data Use Agreement that must be signed before they are delivered. Bottom of Form

In what form is the data provided?

Datasets are provided electronically as de-identified data compiled in an IBM SPSS file format. Other formats may be available upon request. Users are free to convert the files to other formats using commercially available conversion software (e.g. Stat/Transfer).

How may I use the ACHQC Registry Data?

You must disclose to ACHQC your intended research or quality improvement project and that project will be used to define how you are permitted to use the data.

Why am I required to disclose information about industry interest in or funding of my project?

ACHQC surgeons are not permitted to access ACHQC data on behalf of industry.

May I use discretionary funding, even if received from industry, to conduct my research using ACHQC data?

Yes, so long as you are not conducting that research for or at the request of the industry member.

Are there projects that ACHQC will not approve for use of ACHQC Registry Data?

Yes, ACHQC will not approve a project that is being conducted on behalf of industry, any for-profit enterprise, or for the benefit of any third party (other than a surgeon's institution which is a participant in the ACHQC). Governmental and non-profit funders (independent of industry) are not considered third parties for this purpose. ACHQC reserves the right to reject any project that is not consistent with ACHQC's mission or policies and any project that is deemed so broad in scope as to provide no reasonable restriction on the use of the data.

Are there HIPAA and other legal considerations involved in using the ACHQC Datasets?

Although you will receive data in a de-identified, non-protected health information format, you are prohibited from attempting to re-identify any patient, surgeon or health care facility with that data. You are required to involve your institution's Institutional Review Board with respect to any research use of the ACHQC Data.

Are there any restrictions related to the minimum size of data reporting?

Yes, based on federal law and ACHQC's commitments to its participants, you may not use ACHQC Datasets to disclose, publish, or report any outcomes or events which: (i) are less than ten (10) in number, (ii) relate to a geographical area smaller than one of the four Census Bureau Regions (Northeast, Midwest, South, or West) as defined by the United States Census Bureau, or (iii) relate to one participant, surgeon, or site, hospital, or other health care facility.

Are there requirements I must meet to publish or report on the data?

So long as your use is permitted under your data use agreement, you are free to publish and report on the data as you wish. In publishing or reporting on data, however, you are required to include the following attribution and disclosure in your publication or report:

The Abdominal Core Health Quality Collaborative (ACHQC) and the hospitals and surgeons participating in the ACHQC are the source of the data used herein [*or some appropriate description of the portion of the publication using Registry Data*]; ACHQC has not verified and are not responsible for the statistical validity of the data, any analyses made, and the conclusions drawn by the authors.

Who is responsible for the use and content of the ACHQC data?

You are. The ACHQC has protocols, policies, and procedures in place to test the validity and scientific integrity of data, but as a matter of contract ACHQC disclaims responsibility for and you must accept responsibility for your use of the ACHQC data and any analyses you make and any conclusions you draw from that data.

What do I do if I suspect there is an error in the data?

Despite the protocols, policies, and procedures in place to test the validity and scientific integrity of the ACHQC data, it is possible that errors may exist in the data. If you suspect an error in the data, please report your observations to datahelp@achqc.org.

If I have a question about the data, who can I contact?

You may contact datahelp@achqc.org or find more information at www.achqc.org.