

Community Counts *Internal* Use Data Request for Regions and HTCs Guide

This process is intended for Regional or HTC level staff who are seeking data or data reports for internal use only, such as QI. If you are planning to publish or present your data externally, use the [Community Counts Data Use Request Guide](#).

Please follow this step-by-step guide to help you complete your electronic Community Counts *Internal* Use Data Request for Regions and HTCs. It is recommended that you read this document in its entirety before you begin your application.

A complete list of available Community Counts variables can be found on the ATHN support site under the Community Counts tab <https://support.athn.org/>.

Background:

Community Counts: CDC Public Health Surveillance Project for Bleeding Disorders (Community Counts) is a national project of the Hemophilia Treatment Center Network (HTCN) as subcontractors to the American Thrombosis and Hemostasis Network (ATHN) initiated under a cooperative agreement with Centers for Disease Control and Prevention (CDC). The Community Counts project builds upon the important work started through the Universal Data Collection (UDC) project. The project goals are to provide descriptive knowledge about the populations of hemophilia, von Willebrand disease, other bleeding disorders and VTE receiving care at HTCs and to monitor health indicators among populations with bleeding disorders. CDC, ATHN and the HTCN are committed to providing investigators the opportunity to use and analyze data collected as part of Community Counts and/or UDC, consistent with the purposes for which they were collected and patients' authorization for data use. Access to Community Counts and/or UDC data for the purpose of analysis is allowed after completion and approval of the Community Counts Data Use Request submission.

All requestors and collaborators must complete a Terms of Access to Restricted Community Counts Data document prior to the approved data request being fulfilled. This document can be found at <https://athn.smapply.io/>.

Once a request has been submitted, the review process will take approximately 3 weeks depending on the topic and data requested. CDC will review to determine whether it fits the criteria for a limited use request and to provide details about next steps.

Accessing the Electronic Application:

To access the electronic application (request submission), go to <https://athn.smapply.io/>. You can see all open awards/applications currently available at ATHN. Choose the Community Counts Internal Use Data Request and hit the green APPLY button.

Find the log in button at the top left of the screen. You will choose ATHN log in and use your ATHN sign on that you use when registering for the ATHN Data Summit. If you do not have an ATHN sign on or you've forgotten your password, you can follow the directions on the screen.

Once you are in the application, find the tasks in the middle of the screen and click on Community Counts Data Use Request. This will take you directly to the application.

Helpful Hints Before You Get Started:

- ⇒ We recommend that you read this guide prior to completing your electronic application.
- ⇒ You can assign collaborators to work on your electronic application with you. At the left of your application is a section for you to add collaborators. Once you enter a collaborator's email address, they will be sent an invitation to join your application. Collaborators will need an ATHN sign on as mentioned above. It's important to keep in mind that collaborators can edit and enter information but only the owner of the application can submit.
- ⇒ If you have questions while completing your application, please reach out to support@athn.org.

Completing the Electronic Application:

Requestor Information Details

- Name
- Affiliation
- Email address
- Telephone number

Data Request Details

- Summary of Data Request and Intended Use (type or copy/paste)
 - Provide a detailed overview of the request. Please include the purpose of data request, the intended audience, the geographic granularity [e.g., state, regional, HTC], and how the results will be shared).



Community Counts

- What is the desired dataset? (choose all that apply)
 - Mortality data
 - HTC Population Profile (HTC PP) Data
 - Registry Initial Visit Data
 - Registry Subsequent Visit Data
- If HTC PP Data is requested, please specify (choose option)
 - Most recent HTC PP visit
 - First HTC PP visit
 - Other (example, 2014-2018)
- If Registry Subsequent Visit Data is requested (type or copy/paste)
 - Most recent Registry Subsequent visit
 - Other (example, 2014-2018)
- Description of requested data and its content (choose option)
 - Inclusion criteria
 - Exclusion criteria
 - Other data restrictions
- Data range of the requested data (type in date)
 - Start date
 - End date
- What is the desired format of the requested data? (choose option)
 - Line Level Data – Note: Please include a list of the requested variables with this form
 - Data Report – Note: Please include a final table shell with the requested data elements with this form
- Please upload your desired format here: (upload documents based on examples below)
- Requested fulfillment date: Allow at least 3 weeks from submission date (type in date)

SAVE AND CONTINUE EDITING will save your information. **MARK AS COMPLETE** will take you to the next screen. Each page must be completed to be saved.

Submitting the Electronic Application:

Now that you have completed your electronic application, the SUBMIT button on the left of your main application screen has changed to green. Click on the green SUBMIT. The system will confirm that you want to submit. The system will post an acknowledgment confirming that your application has been successfully submitted.

If you would like to download a copy of your submission, you can click on the 3 dots on the top right of the screen. You can do this from the main screen or from your open application.

Review and Approval:

Once a request has been submitted, the review process will take approximately 3 weeks depending on the topic and data requested. CDC will review to determine whether it fits the criteria for a limited use request and to provide details about next steps.

Examples

Example Lists of Requested Variables

(For your convenience, please find a complete list of Community Counts variables [here](#).)

Example 1:

Form Name	Variable Label
Initial Visit Form	Year of Visit
Initial Visit Form	Source
Initial Visit Form	Age
Initial Visit Form	Gender
Initial Visit Form	Primary Diagnosis

Example 2:

Initial Visit Form

Year of Visit

Source

Age

Gender

Primary Diagnosis

Example Line Level Dataset showing patients with Hemophilia A that are enrolled in Community Counts from 2012-2019

Subject ID	Year of Visit	Source	Gender	Primary Diagnosis	Severity	Age
EXAMPLE1	2013	Initial Visit Form	Male	Factor VIII	Mild	34
EXAMPLE2	2017	Initial Visit Form	Male	Factor VIII	Moderate	42
EXAMPLE4	2015	Initial Visit Form	Female	Factor VIII	Mild	12
EXAMPLE5	2012	Initial Visit Form	Female	Factor VIII	Severe	61
EXAMPLE6	2019	Initial Visit Form	Male	Factor VIII	Mild	42

Example Table Shell with Requested Data Elements

	#	%
Severity		
Mild		
Moderate		
Severe		
Age		
0-18 years		
19-44 years		
45+ years		



Presentation and Publication Information:

- ⇒ Once you have obtained your data and completed your project, please keep in mind that all publication or presentation of works using Community Counts data or describing its methodologies must be evaluated and approved prior to submission to an outside organization.
- ⇒ Presentations and publications must be submitted through our electronic system using the same directions for Accessing the Electronic Application included in this document near the beginning. You will choose the Community Counts Presentation and Publication Approval Request application.
- ⇒ Submissions will be reviewed to determine that they are scientifically sound and that they meet the guidelines for authorship. Approval request must be submitted by the lead author. It is the responsibility of the lead author to see that all co-authors have already reviewed the document prior to submission for approval.
- ⇒ Most reviews will take approximately 4 to 6 weeks to complete. Abstracts will be due for submission for review at least 2 weeks prior to the venue submission deadline. Abstract reviews will be expedited.
- ⇒ Any presentation or publication using Community Counts and/or UDC data with CDC personnel as an author must have CDC clearance prior to the submission. Ten-fourteen days after the Community Counts Presentation and Publication Approval should be allowed for clearance of an abstract; six weeks should be allowed for clearance of a manuscript.
- ⇒ The reviewer determinations may be 1) Approve as is, 2) Approve with minor revisions, or 3) Revise and resubmit. Once the reviews are completed, investigators will receive an email notification with the determination and next steps.

Acknowledgement and Disclaimer:

All publications must include the following language:

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If you have any questions, please contact support@athn.org and include “Community Counts Data Use” in the Subject line of your email.