

How and When to Request Approval to Present and/or Disseminate Community Counts Data

The Division of Blood Disorders (DBD) team at Centers for Disease Control and Prevention (CDC) has created tools to help HTC access data and reports related to the Community Counts project. These data and reports are available for HTC Population Profile, Mortality Reporting, and the Registry. There may be times in which you want to present on some of the information available through these resources. Please follow this guide to help you determine when/if you need to submit a request to have your publication and/or presentation reviewed and approved prior to presenting or disseminating to the public.

Data Sources:

- ◇ [CDC Community Counts Data Visualization Tool](#) : Publicly Available
- ◇ DBD Gateway Specimen and Forms Summary: sign on needed
- ◇ DBD Gateway Errors Summary: sign on needed
- ◇ DBD Gateway Demographic Reports: Restricted data – sign on needed*
- ◇ DBD Gateway Diagnosis Reports: Restricted data – sign on needed*

* Prior to access, each person must complete a [Terms of Access to Restricted Community Counts Data](#) document and receive CDC approval. Regional Administrators will also need to approve access.

When to Submit for Prior Review/Approval:

Data Use (Internal audience – sharing with HTC and/or regional staff only)	Review prior to dissemination
Information or graphs from the Data Visualization Tool for any purpose or audience	No
Individual HTC reviewing their own reports	No
Individual HTC participating in their own internal QI	No
Individual HTC reporting their own information	No
More than one HTC in the same region working together on presenting their combined data	No
More than one HTC in the same region working together on a combined QI project	No

Data Use (External audience – sharing with others outside of HTC and/or regional staff)	Review prior to dissemination
Local/chapter conference presentation	Yes
Regional/state meeting/conference presentation	Yes
National/international conference presentation	Yes
Local/state/national publication	Yes
Peer reviewed journal submission	Yes



Concealing Counts of 5 or Fewer Cases When Reporting/Presenting Data:

Condition 7 of the Terms of Access to Restricted Community Counts Data states, “I will avoid reporting or publishing, or indirectly revealing (such as by subtraction), any information that contains counts of 5 or fewer cases except when using data from my own center for purposes consistent with its internal policies and procedures.” This applies to tables, figures and text in the data presentation and includes counts of zero.

Two common ways to avoid revealing small counts are collapsing categories of the characteristic and suppression of the small count(s). Examples of each are provided in the Concealing Counts of 5 or Fewer Cases document.

Submitting Your Presentation/Publication for Review/Approval:

Please keep in mind that publication or presentation of works using Community Counts data or describing its methodologies must be evaluated and approved prior to submission to an external organization. Presentations and publications must be submitted through ATHN’s electronic system. To access the electronic submission portal, go to <https://athn.smapply.io/>. You can see all open awards/applications currently available at ATHN. Choose the **Community Counts Presentation and Publication Approval 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 portal, find the tasks in the middle of the screen and click on Community Counts Presentation and Publication Approval Request. This will take you directly to area to upload your submission. Only the portions of your presentation that use or are related to Community Counts data need to be uploaded for review.

Manuscripts, abstracts, press releases, presentations and other items for publication using Community Counts data or describing its methodologies will be reviewed and approved by the Community Counts review committee prior to submission to an external organization. It is the responsibility of the submitting author to see that all co-authors have already reviewed the document prior to requesting approval.

Review and Approval:

Submissions will be reviewed for issues of participant confidentiality and correct interpretation/use of data elements. The review process may take up to 4 to 6 weeks depending on the type of submission and the level of review required. Once the reviews are completed, investigators will receive an email notification with the determination and next steps. Reviews may be expedited to meet timelines related to presentation deadlines.



Acknowledgement and Disclaimer:

All publications must include the following language:

Community Counts is a project supported by cooperative agreement NU27DD000020 awarded to the American Thrombosis and Hemostasis Network (ATHN) in partnership with the U.S. Hemophilia Treatment Center Network (USHTCN). The cooperative agreement is an annual financial assistance award totaling \$4,300,000 which is 100% funded by the Centers for Disease Control and Prevention (CDC) and the U.S. Department of Health and Human Services (HHS). The contents of this publication are solely the responsibility of the authors and do not necessarily represent the official views of the CDC, the Department of Health and Human Services, ATHN, or the USHTCN. Data reported in this publication were collected through Community Counts: CDC Public Health Surveillance Project for Bleeding Disorders.

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