



Bruce H. Thiers, MD, FAAD President
Kenneth J. Tomecki, MD, FAAD President-elect
Susan C. Taylor, MD, FAAD Vice President
Neal Bhatia, MD, FAAD Vice President-elect
Marta J. Van Beek, MD, MPH, FAAD Secretary-Treasurer
Daniel D. Bennett, MD, FAAD Assistant Secretary-Treasurer
Elizabeth K. Usher, MBA Executive Director & CEO

COVID-19 Dermatology Registry Data Request Process

We recognize the importance of making data related to the COVID-19 pandemic accessible for research purposes. We have a process in place to ensure that all requests are evaluated based on scientific merit. All requests to use this data will be reviewed by the COVID-19 Dermatology Registry Data Governance Workgroup. Click [here](#) to see who we are.

Requests will be reviewed by this international Workgroup prior to approval and are subject to the requester completing ethics and data transfer requirements. The link to the data request application is included at the bottom of this page. The application requires that your research team have a research question, abstract, project outline, statistical analysis plan, and anticipated timeline for your concept. You will also indicate which questions/variables you wish to request from the Data Registry. If your request is approved, you will have to abide by the requirements related to abstracts, manuscripts, and authorship laid out in the application.

Which questions/variables from the Data Registry can I request to access?

A list of the registry questions/variables available for request is linked in the data request application, within the Data Request section. Please email Geoffrey Chen: gchen14@mgh.harvard.edu if you have trouble accessing the list or with any questions you have about the data request process. Please note that some questions were added later on in the study, and some questions include "branching logic" such that not all questions were asked of all participants.

The COVID-19 Dermatology Registry data does include names, professional titles, and email addresses of health care professionals who entered the de-identified patient data. However, in order to maintain privacy of those who have entered cases, requests to contact healthcare providers will generally be denied except in particularly relevant cases.

Please note that the COVID-19 Dermatology Registry does not routinely collect photos of cases entered into the registry.

If approved, is there anything I need to do before receiving this data?

This dataset has been determined not human subjects research by the Partners HealthCare Institutional Review Board. The Partners Healthcare Institutional Review Board does not cover data analysis outside of Partners Healthcare. Therefore, if this data request is approved, the concept lead

CORRESPONDENCE

PO Box 1968
Des Plaines, IL 60017-1968

EMAIL: mrc@aad.org
WEB: aad.org

ROSEMONT, IL OFFICE

9500 W Bryn Mawr Avenue, Suite 500
Rosemont, IL 60018-5216

MAIN: (847) 330-0230
FAX: (847) 240-1859

WASHINGTON, DC OFFICE

1445 New York Avenue, NW, Suite 800
Washington, DC 20005-2134

MAIN: (202) 842-3555
FAX: (202) 842-4355

must contact their own IRB to see if approval is required from their own institution to perform secondary data analysis of de-identified data. In addition, the recipient may need to obtain a data use agreement at their primary institution to access the data within the COVID-19 Dermatology Registry.

If approved, is there anything I need to do before submitting my research to a conference or journal?

All abstracts, manuscripts, and other materials containing COVID-19 Dermatology Registry data must be submitted to the COVID-19 Dermatology Data Governance Workgroup for review and approval prior to submission for presentation or publication. The Workgroup reserves the right to decline permission to submit until revisions have been approved.

Do I need to acknowledge the creators of the Registry in any publications of my research?

The development, distribution and management of this dataset has been made possible by a number of individuals. If this data request is approved, per ICJME requirements, the concept lead will be made aware of co-authors who must be included on any resulting presentations or publications, and would be expected to be included in the manuscript preparation.

At a minimum, the COVID-19 Dermatology Data Registry Concept Team should be included as co-authors on publications. If you need additional expertise, the COVID-19 Dermatology Data Governance Workgroup can recommend other members as well. Authorship discussion should be undertaken with leadership of the COVID-19 Database in the early stages of the project.

To access the data in the COVID-19 Dermatology Registry, please complete this data request application: https://redcap.link/covid19dermreg_datarequest

Please note that you do not need to complete the data request application in one sitting. You can select “Save and Return Later” to save your progress and return to make edits. Once you are ready to submit the completed proposal for review, hit the “Submit” button.