



## Data Access and Use Policies and Processes

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### Introduction

DataDerm was launched in 2016 with the vision to serve as the premier registry to facilitate patient care, research, and teaching in dermatology. As of the end of 2025, DataDerm has data from more than 16 million unique patients and 68 million patient visits. As part of DataDerm’s mission to serve dermatologists and the specialty of dermatology, DataDerm data are available to AAD members to support data-driven projects advancing scientific research, advocacy, and ongoing improvement of patient care and outcomes. DataDerm’s data analytics program aligns with the Academy’s efforts to promote the use of DataDerm as a tool for delivering data-driven insights for the specialty. This document aims to provide a detailed description of policies and processes for data access and use for AAD members. This document does not address data access for stakeholders who are not AAD members or for member data requests that are supported by external funding.



## **Data Governance Task Force**

### Mission

The Data Governance Task Force (DGTF) is charged with overseeing DataDerm's data analytics area, which includes the overall management of the data, development of data reports, and implementation of established policies and processes for data access, and dissemination and use by various stakeholder groups. The Data Governance Task Force makes recommendations to the DataDerm Oversight Committee on these topics.

### Organizational Structure

The DGTF comprises 7 members and reports to the AAD's DataDerm Oversight Committee (DOC). The DGTF Chair provides regular updates on Task Force activities to the DOC and is required to obtain DOC's approval on new initiatives. The Task Force is supported by its staff liaison ([datadermanalytics@aad.org](mailto:datadermanalytics@aad.org)) and receives additional operational support from the DataDerm Analytics team.

## **Data Privacy and Security**

All analyses for DataDerm's data analytics area are performed using a registry dataset in a secure analytics environment in compliance with all applicable statutes and regulations under federal and state laws, including but not limited to the privacy and security regulations promulgated under the Health Insurance Portability and Accountability Act of 1996 (HIPAA) and any other applicable statutes or regulations concerning patient privacy and data security. All data analytics and outputs will be de-identified as required under HIPAA and will be subject to the terms of a data use agreement executed between AAD and the data recipient. The Academy is not permitted to identify or contact the individuals to whom the data pertain.

## **DataDerm Data Request Program**

This section addresses the management of requests for DataDerm data, specifically describing data access, data request submission and selection, data use policies, presentation/publication requirements and related areas.

The AAD accepts DataDerm data requests from a variety of stakeholders and reserves the right to deny data requests at the discretion of the DGTF. Data analysis is conducted by the DataDerm analytics team with oversight from the DGTF. Data requests will be fulfilled using the most recent data available at the time of analysis unless otherwise specified in the data request form.

### Member Eligibility

Any AAD member in good standing is eligible to submit a proposal for the DataDerm Data Request Program. Students and non-fellow members may also submit proposals, but must have the sponsorship of an AAD member, who is not submitting a separate proposal, in their submission. Individuals who hold a leadership position (e.g., board member, elected office, executive committee member, other leadership position) at another registry and/or specialty organization must disclose this outside interest when submitting their data request proposal. Review and adjudication of disclosed outside interests is under the purview of the DGTF, with escalation (e.g., to the



DataDerm Oversight Committee, Executive Committee, other reviewing body) at the discretion of the DGTF chair. Information on the current AAD Governance Structure can be found at <https://www.aad.org/member/membership/cctf>.

### Timeline

The submission window opens during Annual Meeting each year. Requestors will have through the end of April to submit requests via the DataDerm website. Proposals will be compiled, reviewed by staff, and scored by the DGTF. Selected proposals will be notified in June via email. Analytics work will take place through the remainder of the year, with all analytics required to be completed by the end of the program year. DataDerm staff will be available to provide support in development of presentation(s) and/or publication(s) related to the project during the first quarter of the following year. The project is considered complete at the end of the following Annual Meeting.

### Project Eligibility

Proposals that are submitted in full before the deadline will be considered eligible for the Data Request Program. Due to the nature of the request process, each member is allowed to submit one proposal per year. Individuals who submit more than one proposal will have only their last complete submission considered for review. DGTF members are not eligible for project submission or sponsorship, and are expected to recuse themselves from all discussions, voting, and other activities related to those requests which constitute a conflict of interest per the AAD's policies pertaining to management of conflicts of interest.

### Submission

All proposals must be submitted via the portal on the AAD DataDerm Website. All individuals must have an up-to-date COI filed with the academy at time of submission. Applicants should complete all requested information in the proposal submission form to the best of their ability. Any questions related to a proposal submission should be sent to [datadermanalytics@aad.org](mailto:datadermanalytics@aad.org).

### Review and Selection of Proposals

The DGTF will review each proposal individually and score it based on the following criteria: Requestor Eligibility, Proposal Feasibility, Alignment with Academy Strategic Initiatives, & Scientific Merit. All DGTF members will individually score each proposal and those with the highest sum of scores will be selected for the DataDerm Data Request Program. In the case of a tie, proposals will be reviewed in a full DGTF meeting for additional discussion and final adjudication. Final selection will consider both quantitative scoring and qualitative alignment with dermatologic and Academy priorities.

Once all proposals for the program year have been selected, winners will be notified via email that their proposal has been selected. At this time a data use agreement must be signed that outlines the requirements from the requestor throughout the analytics process. Individuals whose proposals were not selected will receive a follow-up email with comments, if possible, for future submission consideration.

### Awardee Requirements & Timeline

Once a proposal has been selected via the process, the analytics process will start. Each proposal will be assigned an AAD Analytics staff member to perform the data analysis. This individual will be responsible for guiding the proposal through the remainder of the process, including data selection and cleaning, analysis, formatting, and

visualization. During this process it is imperative that data requestors be responsive in order to maintain the project timeline and allow for sufficient revisions. Responses should be provided within 2 business days of outreach from analytics staff. Multiple meetings between requestors and analytics staff will be required to ensure that the project stays on track. Meetings should be scheduled promptly.

Final analytics requests, revisions, and data outputs must be complete by the end of the program year. After this time no new analytics may be run, except for updates as needed for publication and presentation purposes. Staff will be available until the AAD Annual meeting of the following year to support with presentation creation and publication writing. Once the following Annual meeting is concluded, no more analytics time is available from the AAD analytics team, and the project will be considered closed.

#### Publication and Projects

All selected data requestors are encouraged to submit a publication and/or present an abstract to ensure new knowledge is disseminated to academy members. Timelines for projects outside of the Annual meeting are the responsibility of the data requestor. Publications and presentations of DataDerm projects should reference the most recent DataDerm Annual Report. Data requestors may be invited to present on their project at the AAD's Annual Meeting. If a requestor is invited to present their project at the AAD Annual Meeting, AAD staff will communicate details and expectations related to the presentation.

#### **Data Requests Outside of the Data Request Program**

Data requests that are operational in nature and support ongoing Academy operations and initiatives (e.g., requests from AAD staff, leadership or CCTFs) do not require DGTF approval for completion. DataDerm participant requests for their own data are not subject to the timelines of the DataDerm Data Request Program and will be processed by the DataDerm analytics team as the requests are received. The DGTF will convene as needed throughout the year to review progress on selected data requests, completed internal requests for DataDerm participants and AAD staff, leadership, and CCTFs, and publications/presentations related to DataDerm.

#### **Presentations and Publications**

The Academy requires all abstracts, manuscripts, and other materials containing DataDerm data to be submitted for review by the DGTF prior to submission for presentation or publication. All publications and presentations must cite the most recent DataDerm Annual Report. PowerPoint presentations, abstracts and manuscripts should be submitted at least 30 days prior to submission for publication, where possible.

Publication plans and authorship expectations will be addressed during the initial kickoff call between DataDerm staff and the data requestors. Authorship roles should be determined in accordance with author criteria of the destination peer-reviewed journal and follow ICJME guidelines. In instances where DataDerm staff do not meet authorship criteria, DataDerm Analysts must be included in the acknowledgements section.

Presentations that feature DataDerm data must appropriately acknowledge DataDerm, including an appropriate citation on any slide(s) which feature DataDerm data.



When describing DataDerm in the text of an abstract or manuscript, DataDerm should be described as the clinical data registry of the American Academy of Dermatology. Authors must cite the most recent DataDerm annual report and the results of our 2020 independent audit when referencing DataDerm data.

Data request investigators are strongly encouraged, but not required, to seek publication of DataDerm data in the Academy's publications (e.g., Journal of the American Academy of Dermatology (JAAD), Journal of the American Academy of Dermatology International (JAADI) Dermatology World, etc.). Abstracts, slide decks (e.g. PowerPoints), manuscripts, or other publications using DataDerm data that include potentially controversial findings may be escalated as necessary (e.g., to the DataDerm Oversight Committee, Executive Committee, Board of Directors, other reviewing body), at the discretion of the DGTF chair. Abstracts, slide decks, manuscripts, or other publications that are intended to represent the position of AAD must be approved by the Board.

If an AAD/A council, committee, task force or work group is interested in obtaining DataDerm data with the intent to publish its work in (JAAD), it must submit a JAAD "From the Academy" Proposal form along with a proposed outline of its manuscript to [jaadmanagingeditor@aad.org](mailto:jaadmanagingeditor@aad.org). Once JAAD approval is received, the council, committee, task force or work group may submit its data request to the DGTF.