The 2020 annual report of DataDerm: The database of the American Academy of Dermatology

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The American Academy of Dermatology launched DataDerm in 2016 as the clinical data registry platform of the American Academy of Dermatology. DataDerm is approved by the Centers for Medicare & Medicaid Services as a Qualified Clinical Data Registry for the Merit-Based Incentive Payment System. The ultimate purpose of DataDerm is to provide dermatologists with a registry and database that will serve as a vehicle to advance the specialty in the domains of science, discovery, education, quality assessment, quality improvement, advocacy, and practice management.

DataDerm is currently the largest clinical registry and database of patients receiving dermatologic care in the world. As of December 31, 2019, DataDerm contained data from 10,618,879 unique patients and 32,309,389 unique patient visits. Depending on the reporting period, 800 to 900 practices (representing 2400-2600 clinicians) actively participate in DataDerm by submitting data.

This article provides the first of a planned series of annual updates of the status of DataDerm. The purpose of this article is to present the rationale for the creation, maintenance, history, and current status of DataDerm, as well as the future plans for DataDerm. (J Am Acad Dermatol 2021;84:1037-41.)

Key words: database; dermatology; outcomes; quality; registry; safety.

The art and science of outcomes analysis, quality improvement, and patient safety continue to evolve at a rapid pace.[1] To equip the specialty of dermatology to remain current in each of these realms, the American Academy of Dermatology (AAD) developed and maintains a clinical registry and database platform: DataDerm. Currently available to all AAD members, the DataDerm registry provides a vehicle for the generation of important new knowledge encompassing the domains of patient care, quality, and safety. DataDerm facilitates the assessment of multiple domains of quality (ie, structure, process, and outcome),[2-6] and it also allows for the measurement of the value of dermatologic care.[7]

Registries and databases serve multiple purposes: the analysis of outcomes, the assessment and improvement of quality, and the generation of new knowledge through observational research.[8] As the official registry and database of the AAD, DataDerm aspires to set the standard for the collection of dermatologic data in all of these domains. This article will be the first in a series of planned annual updates about the status of DataDerm. The purpose of this article is to present the rationale for the creation, maintenance, and expansion of DataDerm, as well as its history, the current status, and future plans.

HISTORY OF DataDerm

With a membership of more than 20,000 physicians worldwide (16,494 members located in the United States and 3941 international members), the AAD represents dermatologists who provide care across

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all patient populations. As an organization, the AAD is committed to advancing diagnosis and treatment within all aspects of dermatology (medical, surgical, and cosmetic) and to advocating for the highest standards in clinical practice, education, and research in dermatology. The AAD launched DataDerm in 2016 as the official clinical data registry of the AAD. The history of DataDerm[9,10] is summarized in the supplemental materials (available via Mendeley at https://doi.org/10.17632/bn3k4ny9vs.2).

CURRENT STATUS OF DataDerm

DataDerm participation

As of December 31, 2019, DataDerm contained data from 10,618,879 unique patients and 32,309,389 unique patient visits. In 2019, nearly 800 practices submitted data, representing 2422 clinicians. Most clinicians submitting data in 2019 were dermatologists (1500), followed by physician assistants (513) and nurse practitioners (186) who are employed by AAD members and meet the AAD definition of the AAD DermCare Team. Detailed information about the providers who have actively submitted data in the past 12 months to DataDerm is provided in Supplemental Table I (available via Mendeley at https://doi.org/10.17632/cgtnkj3zsz.2). Based on the number of demographically diverse patients with a variety of insurance carriers and sources of payment represented in DataDerm, the specialty is now able to see how different patient populations can access dermatologic care throughout the country. Basic demographic information about the patients in DataDerm is provided in Supplemental Table 2 (available via Mendeley at https://doi.org/10.17632/dpp27pcp9r.2).

CAPSULE SUMMARY

- DataDerm is the largest clinical registry of dermatology patients in the world and is a valuable resource for quality improvement and research.
- As of December 31, 2019, DataDerm contained data from 10,618,879 patients and 32,309,389 patient visits. Depending on the reporting period, 800 to 900 practices (representing 2400-2600 clinicians) participate in DataDerm.

DataDerm provides real-world data and information for participating clinicians, practices, and the specialty of dermatology. With this information, participants can demonstrate to payers and the medical community the value of their quality care, meet the reporting requirements of programs such as the Centers for Medicare & Medicaid Services (CMS) Merit-Based Incentive Payment System (MIPS), and satisfy American Board of Dermatology Maintenance of Certification (MOC) Part IV—Practice Improvement.

Every DataDerm participant has access to a real-time DataDerm dashboard. This DataDerm dashboard provides participants with the ability to view data about their own practice in comparison to aggregate benchmark data. Practices and individual clinicians can view and measure their performance in comparison to an aggregation of data from all members participating in DataDerm, as well as available CMS benchmarks. Detailed information about the DataDerm dashboard and sample DataDerm dashboards are provided in Supplemental Figures 1 to 3 (available via Mendeley at https://doi.org/10.17632/tt66wjrv88.2).

Data in DataDerm are currently extracted and derived from structured fields and clinical notes within electronic health records (EHRs). DataDerm currently interfaces with 26 EHRs, allowing data to be uploaded automatically without additional entry of data from the provider. Supplemental Table 3 (available via Mendeley at https://doi.org/10.17632/tysx486237.2) lists diagnoses extracted from EHR-linked practices and stratified into major diagnostic groups. Supplemental Table 4 (available via Mendeley at https://doi.org/10.17632/drxbmsm8pt.2) documents common procedures extracted from EHR-linked practices.

DataDerm and quality reporting

Before the launch of DataDerm, the AAD had facilitated a paper-based mechanism for the submission of quality reporting for members for the Physician Quality Reporting System (PQRS). Shortly before the initial DataDerm launch (2016), the US Congress passed the Medicare Access and Children's Health Insurance Program Reauthorization Act, consolidating several legacy reporting programs (the PQRS, EHR Incentive Program [Meaningful Use], and Value-Based Payment Modifier) under one umbrella. Under the Medicare Access and Children's Health Insurance Program Reauthorization Act, the CMS PQRS transitioned to the CMS MIPS, which in turn encompassed the now comprehensive CMS Quality Payment Program (QPP). Many practices integrating into DataDerm immediately leveraged the registry to meet all requirements of MIPS reporting.

CMS approved DataDerm as a Qualified Registry for the 2016 Physician Quality Reporting System, and beginning in 2017, CMS has approved DataDerm annually as both a Qualified Registry and a Qualified

Abbreviations used:

AAD:	American Academy of Dermatology
AAD:	American Academy of Dermatology Association
CMS:	Centers for Medicare & Medicaid Services
EHR:	electronic health record
IDEOM:	International Dermatology Outcome Measures
MIPS:	Merit-Based Incentive Payment System
PQRS:	Physician Quality Reporting System
PRO:	patient-reported outcomes
QCDR:	Qualified Clinical Data Registry
QPP:	Quality Payment Program
RUC:	Relative Value Scale Update Committee

Clinical Data Registry (QCDR) for MIPS reporting. The designation as a QCDR by CMS allows organizations such as the AAD to develop and submit their own specialty-specific performance measures to CMS for approval for use in the QPP program. As a result, the specialty of dermatology can define quality through the development of dermatology-specific performance measures that are meaningful to patients and physicians. This fulfills the long-term goal of AAD federal advocacy to have AAD physicians take the lead roles in defining and measuring quality for the specialty.

From its inception, the goals of DataDerm were to remove the burden of double data entry for quality reporting through EHR integration while also ensuring that measures positively affected dermatology patients. Going forward, DataDerm will be used to identify gaps in care, which will inform the process of performance measure development. AAD ownership of the performance measurement process will allow the AAD to ensure that measures are developed that are feasible to deploy within a busy practice, are clinically meaningful, and will significantly affect quality.

In 2019, the AAD's Performance Measurement Committee, AAD's Council on Science and Research, and the Executive Committee of the AAD approved a portfolio of newly developed measures for reporting to the CMS QPP. Supplemental Table 5 (available via Mendeley at https://doi.org/10.17632/bpyg7pj8wk.2) documents the 11 QCDR measures for 2020 available in DataDerm. CMS approved these 11 measures for use in DataDerm for 2020. The first 7 measures in Supplemental Table 5 are exclusively available for reporting in the AAD's QCDR. The eighth measure is licensed from the American College of Mohs Surgery. The final 3 measures in Supplemental Table 5 are joint measures with The American Society of Plastic Surgeons. These measures are the result of a multiyear effort by the AAD to increase the number and types of measures for assessing, monitoring, improving, and reporting dermatologic care across a variety of practice types.

In 2018 and 2019, 4 AAD physician workgroups collaborated to develop these meaningful measures of quality and performance, based on a priority list generated by AAD physician members and approved by the Board of Directors of the AAD. These workgroups focused on skin cancer and inflammatory skin disease, and the products of their efforts represent inputs from multiple stakeholders, including patients, balancing clinical relevance, feasibility, and burden of documentation. The effort to develop new measures of performance, quality, and value will be an ongoing process, because it is anticipated that successfully executed measures will improve until they are "topped out." At that point, CMS will retire the topped-out measure from the MIPS measure set, and the AAD will need to provide a replacement to maintain a menu of choices for its members.

The ability to document individual and programmatic measures of structure, process, and outcome,[3-6] to assess the value of care,[7] and then to benchmark these measures of quality and value to regional and national aggregate data will facilitate both quality assessment and quality improvement. As DataDerm evolves, individual and practice-level benchmarking of dermatologic care will be critical to facilitate ongoing progress. Recognizing that DataDerm participation allows dermatologists to review their practice dashboard in comparison to other participants and make quality improvements in real time, the American Board of Dermatology now recognizes participation in DataDerm as meeting the requirements of Maintenance of Certification Part IV—Practice Improvement.

DataDerm: Severity of disease and patient-reported outcomes

Congruent with intent of DataDerm to demonstrate the outcomes, quality, and value of dermatologic care, the AAD collaborated with the International Dermatology Outcome Measures organization (IDEOM) (http://dermoutcomes.org/) in 2018 to develop outcome measures for clinical dermatology practice that could be used across multiple inflammatory dermatology disorders. By using a modified Delphi process, a single physician global assessment tool to measure disease outcomes for psoriasis, atopic dermatitis, and acne was selected.[11] The intent of this initiative was to have a single tool that could be used to monitor the severity of disease and progression or improvement throughout the regiment of treatment. Additionally, the AAD collaborated with IDEOM to select patient-reported outcome (PRO) tools for patients with psoriasis, atopic dermatitis, and acne to use in clinics to assess response to treatment.[12] The goal is to use simple physician global assessment and PRO tools to measure disease outcomes and response to treatments in routine clinical practice.

DataDerm and research

As the DataDerm registry matures, it will become an increasingly valuable source of data for dermatologic research. A detailed discussion of the current and potential future roles of DataDerm in dermatologic research[13-19] is summarized in the supplemental materials (available via Mendeley at https://doi.org/10.17632/5m6gzzcmm5.2).

DataDerm and advocacy

The AAD Association (AADA) serves as a resource for dermatologists to interface with governmental affairs, health policy, and the challenges of practice management. The AADA plays a major role in formulating policies that can enhance the quality of dermatologic care. Data from DataDerm will be critical to support the advocacy efforts of the AADA with multiple governmental agencies and professional organizations and societies, including CMS, the US Food and Drug Administration, the Current Procedural Terminology Editorial Panel, and the Relative Value Scale Update Committee (RUC). For example, the RUC now accepts data from approved registries of professional medical societies as a factor when reviewing and recommending the value of medical and surgical services. In addition, demonstrating continuous specialty-wide improvement through the registry supports the advocacy efforts of the AAD.

Audit: The completeness and accuracy of data in DataDerm

The value of data in any registry or database is only as good as the completeness and accuracy of the data. In 2020, DataDerm is undergoing its first audit of data quality to assess both the completeness and accuracy of the data. The AAD has contracted with Telligen (to perform this audit (https://www.telligen.com/). During the audit, fields of data within DataDerm will be compared to source data in individual EHRs. A detailed discussion of the DataDerm audit[20] is summarized in the supplemental materials (available via Mendeley at https://doi.org/10.17632/r68j7xvy5d.2).

THE FUTURE OF DataDerm

In the future, DataDerm has the potential to allow the field of dermatology to achieve multiple objectives:

- measure and assess the quality and value of dermatologic care at both micro and macro levels;
- provide a platform for benchmarking individual and programmatic measures of structure, process, and outcome, in comparison to national (and potentially international) aggregate data so that clinicians and practices can undertake local data-driven quality improvement activities;
- systematically and continuously improve quality;
- generate new knowledge through health services research;
- provide data demonstrating the value of dermatologic care for use when advocating for the specialty to multiple governmental agencies including CMS, the US Food and Drug Administration, the Current Procedural Terminology Editorial Panel, and the RUC; and
- provide real-world evidence to inform federal and state legislative and regulatory initiatives that affect dermatologic care.

Multiple short-term and midterm future initiatives for DataDerm exist. Completion of the current ongoing audit and development of a periodic process of audit is one current priority. Completion of the audit will also facilitate use of DataDerm data by various stakeholders within the dermatology ecosystem. Our next priority is to integrate academic medical centers, which will bring new populations of patients into the registry, increasing its value to many stakeholders. In fact, DataDerm has already conducted a successful pilot for integration with a user of Epic (https://www.epic.com/) at a major academic medical center.

DataDerm is currently mapping strategies to capture additional outcomes and quality data through multiple approaches. The AAD and its Ad Hoc Task Force on Data Collection Platform and Registries are cultivating partnerships with disease and outcomes specialty groups, such as IDEOM, to create standards of measurement and documentation, which will include PRO tools. We are also exploring partnerships that will allow us to deploy novel approaches to create structured data from the free-text fields in the notes of EHRs. Although our current data extractions may be limited to what is already structured within EHRs, these initiatives will make the data within DataDerm even more valuable to AAD and our partners. This enhanced data set will facilitate developing strategies to allow DataDerm to function as a platform for postmarket surveillance and potentiate the concept of DataDerm serving as a platform for a randomized trial within a registry. Because of its size, DataDerm has the potential to examine skin health in large populations and offer opportunities for outcomes research and the study of rare diseases. These efforts could transform the practice of dermatology.

SUMMARY

DataDerm is currently the largest clinical registry of patients receiving dermatologic care in the world. As DataDerm grows, it will further support outcomes analysis, quality improvement, and research. The ability of dermatology to prove its value within the house of medicine requires data showing that dermatologists treat serious disease and improve the lives of our patients. DataDerm is an important resource to the profession of dermatology; however, the viability of DataDerm is dependent on the participation of our members. It is hoped that as DataDerm grows in value, so too will participation increase in this important tool going forward. This DataDerm 2020 annual report represents the first in a series of publications that will allow the AAD and its Ad Hoc Task Force on Data Collection Platform and Registries to convey timely summaries of important topics related to dermatologic quality of care, safety, and—most importantly—health outcomes.

Conflicts of interest

Dr Resneck serves on the Board of Trustees of the American Medical Association and the Board of Directors of the National Quality Forum. The views expressed are those of the authors and do not necessarily represent the views of the American Medical Association or the National Quality Forum. Drs Van Beek, Swerlick, Mathes, Hruza, and Pak; Authors Kaye, Aninos, and Agregado; and Drs Fitzgerald and Jacobs have no conflicts of interest to declare.

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