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International collaboration and rapid harmonization across dermatologic COVID-19 registries



To the Editor: Across specialties, coronavirus disease-2019 (COVID-19) has ushered in an unprecedented time for international collaboration. As COVID-19 has spread around the world, there has been a movement among dermatologists to better understand the effects of the virus on their patients as well as potential dermatologic manifestations of the disease. During March and April 2020, 8 dermatologic registries focused on COVID-19 were launched worldwide to address these issues (Table 1).¹⁻³ We developed a rapid consensus among registry leaders to foster collaboration and data harmonization.

Members from each international registry came together in a virtual consensus meeting in April 2020, facilitated by the American Academy of Dermatology and the International League of Dermatologic Societies. Models of collaboration discussed were (1) linking data across registries for overlapping conditions at the point of data entry and (2) harmonizing data post hoc, using shared variables across registries. As a first step, each dermatologic registry provided a list of the variables they collect across several domains, including registry information, patient demographics, general medical information, prior dermatologic conditions, new-onset skin manifestations in the setting of COVID-19, and COVID-19–related history and outcomes (Supplemental Table 1 available via Mendeley at <https://data.mendeley.com/datasets/zh6bw88xhc>).

This effort formed the basis for a meta-catalog containing all registry variables so that commonalities and variables in need of harmonization between studies could be easily identified (Supplemental Appendix). As a result of this harmonization process, 2 registries have, for example, changed how they collect demographics to harmonize with other international registries. Additionally, the registries now link to each other to facilitate collaboration at the time of data entry.

Registry leaders also discussed challenges in collaboration, particularly double data entry across different registries.⁴ To address this concern, registries added a question at the point of data collection about whether a provider entered a case in another registry and to identify that registry. This additional information will enhance our ability to track double case reporting during analysis, although it is not possible to fully verify deidentified patient data.

An additional limitation is that registries have, thus far, originated from North America, Europe, and

Australia. Even though many of these registries are open to global submissions, most are only available in English, which may hinder participation. Active work is needed to include a broader representation of global dermatologists as well as inclusion of patients from all racial/ethnic and socioeconomic groups within each country.⁵

Ultimately, the reports generated from these registries will only be as good as the data entered. As physicians and researchers, we must strive to include diversity in these reports so that data collected are representative of the global patient community we look after. Communication and transparency in data sharing, which may take the form of regularly posted aggregate data from the registries as well as periodic update newsletters to dermatology societies internationally, may be a motivator for the dermatology community and may encourage engagement and reporting of cases. Together, we are most powerful when our collective knowledge is used to inform the management and care of our patients affected by COVID-19.

The Surveillance Epidemiology of Coronavirus (COVID 19) Under Research Exclusion (SECURE)-Atopic Dermatitis (AD) Registry would like to acknowledge key support through Steering Group and patient partners Bernd Arents and Tim Burton as well as their Statistical Lead David Prieto-Merino and Steering Group members Drs Annelie H. Musters, Angela Bosma, Aaron Drucker, Kenji Kabashima, and Ching-Chi Chi. SECURE-AD and SECURE-Alopecia wish to acknowledge the support of the not-for-profit company, National and International Skin Registry solutions (NISRS) in establishing and maintaining their registries. The Global Hidradenitis Suppurativa COVID-19 Registry would like to acknowledge instrumental Steering Committee members, including John W. Frew, MBBS, MMed, MSc, Sandra Guillbault, Michelle A. Lowes, MBBS, PhD, and Christine A. Yannuzzi, BA. The American Academy of Dermatology/International League of Dermatologic Societies registry would like to thank the staff of the American Academy of Dermatology and the staff of the International League of Dermatologic Societies for their support. All registries would like to thank health care providers worldwide for entering cases.

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Table I. General, demographic, and medical information included in coronavirus disease 2019 (COVID-19) dermatology registries

Variable	PsoProtect	COVIDSKIN French registry	SECURE Psoriasis	SECURE AD	Global HS COVID-19 Registry	SECURE Alopecia	AAD/ILDS Derma- tology COVID Registry	PeDRA
Date initiated	March 27, 2020	March 30, 2020	April 1, 2020	April 1, 2020	April 6, 2020	April 8, 2020	April 8, 2020	April 20, 2020
Website hosted on	www.psoprotect.org	https://bit.ly/COVIDSKINSFD	covidpso.org	covidderm.org	https://hscovid.ucsf.edu	securealopecia.covidderm.org	www.aad.org/covidregistry	pedsderm.net ; pedraresearch.org
Server platform	REDCap*	sfdermato.org	REDCap	OpenApp: Clinical Insight [†]	REDCap	OpenApp: Clinical Insight	REDCap	REDCap
Languages available	English only	French only	English only	English, Chinese, Spanish, French, Russian	English only	English only	English only	English only
Inclusion criteria								
Person entering data	Health care professional or patients	Health care professional	Health care professional	Health care professional or patients	Health care professional or patients	Health care professional	Health care professional	Health care professional
COVID-19 laboratory confirmed	✓	✓	✓	✓	✓	✓	✓	✓
COVID-19 suspected	✓	✓	...	✓	✓	✓	✓	✓
Patients on systemic medication included	✓	✓	✓	✓	✓	✓	✓	✓
Patients not on systemic medication included	✓	✓	✓	✓	✓	✓	✓	✓
Patient demographics								
Date of entry into study	✓	✓	✓	✓	✓	✓	✓	✓
Sex	✓	✓	✓	✓	✓	✓	Assigned at birth	Assigned at birth

Age/year of birth	✓	✓	✓	✓	✓	✓	✓	✓
Country of residence	✓	✓	✓	✓	✓	✓	✓	✓
State of residence	✓		US only	US/Australia	✓	US/Australia	US only	US States/ Canadian Provinces
Ethnicity	✓		US census categories	WHO categories	Originally US Census; changed to WHO categories 4/26/20	WHO categories	Originally US census; changed to WHO 4/20/20	Currently US census categories
General medical information								
Height	✓		✓	✓		✓		
Weight	✓		✓	✓		✓		
Comorbidities (eg asthma, COPD, heart disease, DM)	✓	✓	✓	✓	✓	✓	✓	✓
Smoking status	✓		✓	✓	✓	✓	✓	
Alcohol intake	✓		✓					
NSAIDS	✓			✓	✓	✓		
Existing dermatologic condition								
Primary dermatologic condition	✓	✓	Only psoriasis	Only AD	✓	Only alopecia	✓	✓
Subspecialty disease subtype	✓		✓ Psoriasis subtype			✓ Alopecia subtypes		✓
Year of dermatologic diagnosis	✓			✓		✓		
Name of dermatologic medication	✓	✓	✓ Psoriasis medications only	✓	✓	✓	✓	✓

Continued

Table I. Cont'd

Variable	PsoProtect	COVIDSKIN French registry	SECURE Psoriasis	SECURE AD	Global HS COVID-19 Registry	SECURE Alopecia	AAD/ILDS Derma- tology COVID Registry	PeDRA
Systemic medication:								
Name	✓	✓	✓	✓	✓	✓	✓	✓
Dose and frequency	✓		✓	✓	✓	✓		
Length of treatment	✓			✓	✓	✓		
Stopped or tapered during COVID-19 infection	✓		✓	✓	✓	✓		
Symptom activity at time of COVID-19 diagnosis	✓	✓	✓		✓	✓	✓	
Associated skin disease flare with COVID-19	✓		✓	✓	✓	✓	✓	
Skin disease severity during COVID-19 flare	✓		✓	✓		✓	✓	

AAD, American Academy of Dermatology; AD, atopic dermatitis; COPD, chronic obstructive pulmonary disease; COVID-19, coronavirus disease 2019; DM, diabetes mellitus; HS, hidradenitis suppurativa; ILDS, International League of Dermatological Societies; NSAIDS, nonsteroidal anti-inflammatory drugs; PeDRA, Pediatric Dermatology Research Alliance; SECURE, Surveillance Epidemiology of Coronavirus (COVID 19) Under Research Exclusion; REDCap, Research Electronic Data Capture; US, United States; WHO, World Health Organization.

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(ILDS). Dr Griffiths is president of the European Society for Dermatological Research and is funded in part by the National Institute for Health Research Manchester Biomedical Research Centre. Dr Flohr is president of the British Society for Paediatric Dermatology and chief investigator of the UK-Irish Atopic eczema Systemic Therapy Register (A-STAR; ISRCTN11210918). Dr Flohr and the patient-facing part of the SECURE-AD registry are supported by the National Institute for Health Research Biomedical Research Centre at Guy's and St Thomas' National Health Service Foundation Trust, London, United Kingdom. Devon McMahon and Drs Irvine, Spuls, Ingram, Balogh, Wall, Meab, Sinclair, and Fitzgerald have no conflicts of interest to disclose.

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