clinicians who do not specialize in SSc will be able to suspect SSc more easily, leading to a closer examination for the diagnosis of SSc. Moreover, even if there are no SSc specialists in the vicinity, a strong suspicion of SSc may motivate initial clinicians to refer patients to SSc specialists in remote areas. This could lead to an improvement in the outcomes for patients with SSc.

Ethical considerations
All study participants provided written informed consent, and the study design was approved by The University of Tokyo’s (Japan) ethics review board. This study complies with the Declaration of Helsinki.

Data availability statement
Datasets related to this article can be found at https://doi.org/10.17632/b3h99pywbf.4, hosted by Mendeley Data.

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CONFICT OF INTEREST
The authors state no conflict of interest

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SUPPLEMENTARY MATERIAL
Supplementary material is linked to the online version of the paper at www.jidonline.org, and at https://doi.org/10.1016/j.jid.2021.03.020.

REFERENCES

Validation of Patient-Reported Psoriasis Diagnosis from a Global Online Research Network


TO THE EDITOR
Psoriasis is a chronic, immune-mediated inflammatory systemic disease that affects approximately 2–4% of the world population (Paris et al., 2020; Rachakonda et al., 2014). The diagnosis of psoriasis is typically made clinically by trained clinicians, including dermatologists, general practitioners, and rheumatologists. Although a skin biopsy can be informative in selected cases, the majority of psoriasis diagnoses are established without the need for further laboratory or tissue investigations.

Online platforms that collect patient-reported outcomes have the potential to
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Figure 1. Process for evaluating patient-reported physician-given psoriasis diagnosis. Inquiry of who made the psoriasis diagnosis (top square): a board-certified dermatologist (left middle square) or a provider other than board-certified dermatologist (right middle square). If a board-certified dermatologist made the diagnosis, written or verbal confirmation was obtained by the board-certified dermatologist (left bottom square). If a provider other than a board-certified dermatologist made the diagnosis, written or verbal confirmation was obtained by the provider who made the diagnosis (bottom middle square), and the study board-certified dermatologist reviewed the medical records and/or reviewed the examination clinical findings (bottom right square).

inform clinicians, researchers, and other stakeholders about how individuals experience their disease. They enable efficient collection of patient-reported data from anyone with an internet connection. Few robust online platforms exist in psoriasis where patients provide structured data using validated outcome measures. Importantly, the validity of patient-reported psoriasis diagnoses is critical yet unknown for these online platforms.

Validation of psoriasis diagnoses from large databases has been done by various means. Typically, criterion validity for psoriasis diagnosis is established using the gold standard of diagnosis given by a board-certified dermatologist (Asgari et al., 2013). However, if psoriasis is diagnosed by a provider other than a board-certified dermatologist, such as a primary care physician, additional review of the medical records by a board-certified dermatologist and/or examination of clinical photographs may be necessary to confirm the diagnosis. For example, previous studies validating psoriasis diagnoses used several approaches, including examination of medical records (Asgari et al., 2013), further communication with the provider by the study dermatologist (Asgari et al., 2013; Kurd and Gelfand, 2009), or evaluation of clinical photographs (Asgari et al., 2013; Kurd and Gelfand, 2009).

CitizenPsScientist is crowd-sourced research database created in August 2013 by the National Psoriasis Foundation and approved by the Genetic Alliance Institutional Review Board. CitizenPsScientist purports to determine psoriatic disease burden, natural history, and treatments (National Psoriasis Foundation, 2018). As of June 2020, CitizenPsScientist consists of approximately 3,975 participants who have a self-reported, physician-given diagnosis of psoriasis and have completed online surveys about their overall health and psoriatic diseases. The aim of this study was to validate the patient-reported, physician-given diagnosis of psoriasis within the patient research network CitizenPsScientist. This study is important because having an accurate diagnosis of psoriasis is foundational to subsequent research on comorbidities, disease burden, and health-related QOL.

With an Institutional Review Board (Genetic Alliance, CITP002) approval, we conducted a study to validate the diagnosis of psoriasis among patients who self-reported a physician-given diagnosis of psoriasis from 2013 to 2019. Patients who established an account with CitizenPsScientist and reported having a physician-given diagnosis of psoriasis were randomly selected to participate in the study. Written informed consent was obtained. The patients were asked to provide information about their provider and permission to obtain their medical records and/or clinical photographs. A trained medical record abstractor with extensive experience in psoriasis reviewed the medical record and consulted with the board-certified study dermatologist where clarification was necessary.

The self-reported, physician-given diagnosis of psoriasis was considered valid using established methods for validating psoriasis diagnosis (Asgari et al., 2013). If the diagnosis of psoriasis was made by a board-certified dermatologist, as documented in the medical chart or in a written statement, the diagnosis of psoriasis would be considered valid (Figure 1). Alternatively, if the patient’s provider was not a board-certified dermatologist, the trained abstractor and the study dermatologist evaluated the medical records and/or asked the provider to confirm the psoriasis diagnosis through a written statement or a phone conversation with the study dermatologist. If the patient’s provider could not be reached after multiple attempts, the patient was asked to provide clinical photographs of skin lesions to the study dermatologist. After evaluating the available information, the study dermatologist determined whether the patient had the diagnosis of psoriasis. A sample size of at least 100 patients enabled us to detect within <5% of the true rate of psoriasis if the estimate from the study is above 93%.

A total of 106 patients responded (86.9% response rate); the mean (±SD) age of the respondents was 59 (±12.9) years, and 61% of them were female. Of these 106 patients, an accurate diagnosis of psoriasis was confirmed for 105 patients. Specifically, a total of 75 respondents (66%) had psoriasis diagnosed by board-certified dermatologists, 30 (28%) had psoriasis diagnosed by providers other than board-certified dermatologists. Of these 30 patients, 16 were diagnosed by primary care physicians, 12 were diagnosed by

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rheumatologists, and 2 were diagnosed by nurse practitioners. One patient (0.9%) was identified as a false positive. Specifically, this patient’s primary care physician was no longer practicing and no longer had access to medical records; the patient also did not have active psoriasis lesions that could be photographed for evaluation. On the basis of the data from the entire respondent cohort (106 patients), the positive predictive value of the patient-reported physician-given diagnosis of psoriasis is 99.0% (95% confidence interval: 97.2–100).

This study is among the first efforts to validate the physician-given diagnosis of skin disease from a crowd-sourced online platform. The study findings corroborate the validity of patient-reported diagnosis from other crowd-sourced online databases in non-dermatology fields. For example, a study in the United Kingdom found that the positive predictive value of self-reported physician-given diagnosis of diabetes was 95% (Pastorino et al., 2015). In another study involving patients presenting to the emergency department, their self-reported physician-given diagnosis of chronic obstructive pulmonary disease was 98% (Radeos et al., 2009).

The study sample consisted of potentially motivated participants providing data to the National Psoriasis Foundation and may not reflect other patients with psoriasis in the general population. Compared with the general population with psoriasis where roughly 50% are female, this study has a slight preponderance of women (61%). These study limitations need to be considered when attempting to generalize the findings to the general population.

In conclusion, high validity exists in self-reported physician-given diagnosis of psoriasis in the crowd-sourced online platform Citizen Pscientist. Crowd-sourced online databases examining chronic skin diseases can be a valid method for identifying patients with psoriasis. With the establishment of the validity of self-reported physician-given diagnoses, these crowd-sourced databases can be used to inform the epidemiology, lived experience, and the natural history of chronic skin diseases.

Data availability statement

Datasets related to this article can be found at https://data.mendeley.com/datasets/jg6wjd3j6g/1, an open-source online data repository hosted at Mendeley Data (Armstrong et al., 2021).

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CONFLICT OF INTEREST

AWA serves as a research investigator and/or scientific advisor to AbbVie, Bristol-Myers Squibb, Incyte, LEO Pharma, UCB, Janssen Pharmaceuticals, Eli Lilly, Novartis, Ortho Dermatologics, Sun Pharma, Dermavant, Dermira, Sanofi, Regeneron Pharmaceuticals, Pfizer, and Modernizing Medicine. WL is supported by grants from the National Institutes of Health U01-AI119125 and National Psoriasis Foundation and has received research grant support from AbbVie, Amgen, Janssen Pharmaceuticals, LEO Pharma, Novartis, Pfizer, Regeneron Pharmaceuticals, and Trex Bio. GG and SB are employees of the National Psoriasis Foundation. The remaining authors state no conflict of interest.

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