# Agreement Between Self-reported Inflammatory Skin Disorders and Dermatologists' Diagnosis: A Cross-sectional Diagnostic Study

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E-epidemiology is having a revolutionary impact on the way we monitor global health outcomes and behaviour (1, 2). It presents many advantages, of which a reduction in costs and administrative burden is an important part. Digital data are frequently collected directly from individuals using self-questionnaires. The quality of self-questionnaires in assessing a diagnosis or collecting different data related to a specific disease must be at least equivalent to information collected more traditionally by public health agencies (3–8). The aim of this paper was to study skin autoimmune/ autoinflammatory diseases that are frequent and have a profound impact on quality of life (9-11). The standard for diagnosis of these skin diseases is a physical examination by a board-certified dermatologist. Thus, in the absence of examination by a dermatologist, no reliable tool exists to confirm the diagnosis of a skin disease. Thus, the objective of this study was to identify patients who accurately report their inflammatory skin disorders, especially hidradenitis suppurativa (HS), psoriasis and vitiligo.

# **METHODS**

The study was approved by the Ile-de-France IV (Paris, France) ethics committee (IRB), number 2016/41NI.

Self-reported questionnaires for HS, psoriasis and vitiligo were developed by a panel of 6 experts in dermatology and contained 10, 9 and 8 items, respectively. These questionnaires were based on the model by Dominguez et al. (8) (Fig. S1<sup>1</sup>), with 2 sections: (i) a declarative section (Questions (Q) 1-4) that helps to identify whether the patient thinks he/she has the disease of interest, and who diagnosed it (general practitioner, dermatologist, other specialist physicians, the patient; these items were not exclusive); and (ii) a section (Q 5 to 8-10, details provided in the Appendix S1<sup>1</sup> for each skin disorders) offering a photographic panel of the disease of interest and/or questions regarding the features of disease in its most common phenotypes, and/or questions regarding differential diagnosis. These questionnaires may therefore contain redundant items, but they enable assessment to be carried out with the optimum comprehension by patients between pictures and text. Age and sex were recorded for all questionnaires.

#### Participants

The study was carried out from 5 to 25 January 2016. Questionnaires were distributed to all consecutive out-patients aged 15 years and over, who were attending a consultation in 2 departments of Dermatology located in the University Hospital Centers of Creteil and Bordeaux. Consultations were general, emergency or for specialized dermatoses.

The questionnaires were completed by patients before the consultation, and the dermatologist completed the final part, which attests the presence or absence of 1 of the 3 diagnosis, regardless of the patient's answers. The diagnosis of vitiligo was made by physicians during clinical examination, as were diagnoses of psoriasis or HS, if the patients had flares of the diseases. For patients with no visible lesions, physicians asked about medical history and previous medications used.

#### Algorithms

To avoid item redundancy, we built logical algorithms (using combinations of questions) that assigned a diagnosis of HS, psoriasis or vitiligo, in order to choose the simplest one for each disease. The algorithms are summarized in Table SI<sup>1</sup>.

#### Statistical analysis

*Estimation of sample size.* Based on previous study data (6, 8), we assumed values for sensitivity and specificity of 0.90 (standard deviation (SD) 0.045) at the patient level, which required a minimum of 531 subjects to reject the null hypothesis that either sensitivity or specificity is  $\leq 0.80$  in favour of the alternative > 0.80 (alpha of 0.05 and beta of 0.10) (15).

The population for the analyses included participants who completed all questions for each disorder. Thus, any participant with missing data on one or more questions for one of the skin disorders was excluded from the analyses for the disorder of interest. Metrological characteristics (sensitivity, specificity, area under the curve) were calculated for all logical algorithms (Table SII<sup>1</sup>). The goal of the analyses was to identify the algorithms with the highest sensitivity in distinguishing HS (psoriasis or vitiligo) from non-HS (non-psoriasis or non-vitiligo) in an adult population attending an outpatient dermatology clinic.

Analyses were performed using STATA Version 14 software (Stata Inc., College Station, TX, USA). All tests were bilateral, where  $p \le 0.05$  was considered significant.

Discrete variables are presented as numbers (%).

## **RESULTS**

In all, 534 participants, with a median age of 49 years (age range 15–93 years), 294 women (55.8%) were included. Forty-five participants (30 women and 15 men; median age 34, range 18–76 years) were diagnosed with HS by the dermatologist; 89 with psoriasis (42 women, median age 53, range 17–82 years); 49 with vitiligo (28 women, median age 30, range 18–83 years).

Table SII<sup>1</sup> summarized the metrological characteristics of all the algorithms used to define HS, psoriasis and vitiligo.

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For all the diseases, declarative combinations, particularly algorithm 2: "I have the disease and it was diagnosed by a dermatologist" had excellent sensitivity (Se) and specificity (Sp): Se 92.3% and Sp 96.7%, receiver operating characteristic (ROC) curve 0.94 (0.89-1) for HS, Se 85.7% and Sp 97.5%, ROC curve 0.92 (0.88–0.95) for psoriasis and Se 80.3% and Sp 100%, ROC curve 0.90 (0.85–0.95) for vitiligo. The metrological characteristics of algorithm 4"I have the disease and it was diagnosed by a doctor" were still excellent, with a ROC curve greater than 0.9. The metrological characteristics of algorithm 5 "I have the disease and it was diagnosed by myself" had a fair-to-good ROC curve.

Algorithms with photographs had only worthless-to-fair sensitivity (range 56.3–73.5%). The association between photographs and declarative questions (e.g. I have the disease) improved the metrological characteristics of the algorithms. However, such algorithms still had poorer metrological characteristics than those algorithms with declarative questions only, except for psoriasis (no difference between algorithm 9 and algorithms 2 or 4).

# DISCUSSION

This study highlights that patients who report having psoriasis, HS or vitiligo diagnosed by a physician, especially a dermatologist, report their diagnosis accurately. The results are consistent with already published studies, as such simple algorithms had high sensitivity and specificity for psoriasis and lupus (Se 93%, Sp 98% and Se 91.7%, Sp 93.5%, respectively) (6, 8). Similar results for psoriasis in USA and France at 2 different times (2009, 2016) strengthen our conclusion.

The strengths of this study are the large sample size and its multicentre character, permitting a significant diversity of cases. Furthermore, a strong gold standard was chosen, as the confirmation of diagnosis of skin diseases is based on physical examination by a board-certified dermatologist. It is important to note that the dermatologist who examined the patient during the consultation was different from the dermatologist who made the initial diagnosis of the skin disease as the 2 centres are referral centres. Regarding the limitations of this study, choosing a short questionnaire with a limited number of photographs could lead to a possible selection bias because atypical phenotypes are not taken into account. However, such rare phenotypes usually account for a very low number of patients. A further limitation is that people who attend university hospital centres probably have a better knowledge of their disease compared with the general population. This latter limitation should be put in perspective with the fact that these questionnaires are intended to be used in e-cohorts. In fact, participants in e-cohorts are usually also more concerned with their health. Finally, as the declarative part of the questionnaires was not clearly related to the initial diagnosis, the item "diagnosis by a non-dermatologist doctor" would perform better as a result.

In conclusion, this study identified patients with accurate self-reported diagnosis of skin autoimmune/autoinflammatory diseases using self-administered questionnaires for psoriasis, HS or vitiligo, with simple declarative items such as "Do you have the disease and was it diagnosed by a doctor?". Such algorithms will be of use in selecting population of interest from self-administrative cohorts.

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