The International Dermatology Outcome Measures (IDEOM) Initiative: A Review and Update

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Abstract

The International Dermatology Outcome Measures (IDEOM) group, comprising patients, physicians, health economists, industry partners, payers, and regulatory agencies, was established to develop unified and validated patient-centered outcome measures in dermatology in response to increasing demand to quantify effectiveness of treatments and performance outcomes among providers. IDEOM has chosen to start with psoriasis outcome measures, and then apply its methodology to other dermatologic diseases. In this paper, we review the background and progress to date of IDEOM, including an update of IDEOM activities as of our 2016 meeting in Washington DC, USA. Briefly, the progress-to-date of a Delphi process to create outcome measures for psoriasis was reviewed, including preliminary data from the first round of Delphi voting. Updates were also heard from industry partners including the National Psoriasis Foundation (NPF) and the US Food and Drug Administration (FDA). Furthermore, plans to establish outcome measures for hidradenitis suppurativa (HS) were discussed.

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BACKGROUND

There is a need in dermatology to create standardized, validated, and patient-centered outcome measures that satisfy the needs of all stakeholders, including patients, health care providers, regulators, payers, and industry partners.The goal of these outcome measures should be to assess disease course and response to treatments, as well as to improve patient outcomes and access to quality care. Currently, the lack of standardized, validated outcome measures for most dermatologic diseases contributes to the dif culty in assessing value of treatments supporting third-party payment for appropriate dermatologic care. Since decisions regarding treatment choice are increasingly dictated by payers in the United States, without validated outcome measures, patients may not be able to access providers and treatments that may be beneficial.[1,2] Furthermore, US payers are increasingly demanding of disease-specific outcome measures demanded by both patients and physicians that can be easily used in the clinical setting.[3] Complicating the picture is that current outcome measures may lack truth, discrimination and feasibility.[4] For example, the Psoriasis Area and Severity Index, one of the major outcome measures in psoriasis trials, has many flaws – it is not practical in the clinical setting, it is not responsive to change in patients whose disease covers lower body surface area, and it does not include all skin, hair, and nail area involved.[5,6] Furthermore, assessments of psoriasis disease burden often do not include measures to quantify quality of life or associated risk factors, such as cardiovascular disease and depression. Lastly, none of the established outcome measures in psoriasis were created with any patient input.7,8 The International Dermatology Outcome Measures (IDEOM) initiative was established to address these concerns, with the mission statement, “[To] establish patient-centered measurements to enhance research and treatment for those with dermatologic disease.” The processes that IDEOM has utilized to develop outcome measures for dermatology have been guided by those established by the Outcome Measures in Rheumatology (OMERACT) initiative.

Outcome Measures in Rheumatology (OMERACT)

Outcome Measures in Rheumatology (OMERACT) was initiated by rheumatologists in the 1990s, which led to the development of many core outcome measures currently used in rheumatologic clinical trials.[4,9] The OMERACT process begins by gathering

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