Defining Outcome Measures for Psoriasis: The IDEOM Report from the GRAPPA 2016 Annual Meeting

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ABSTRACT. The International Dermatology Outcome Measures (IDEOM) psoriasis working group was established to develop core domains and measurements sets for psoriasis clinical trials and ultimately clinical practice. At the 2016 annual meeting of the Group for Research and Assessment of Psoriasis and Psoriatic Arthritis, the IDEOM psoriasis group presented an overview of its progress toward developing this psoriasis core domain set. First, it summarized the February 2016 meeting of all involved with the IDEOM, highlighting patient and payer perspectives on outcome measures. Second, the group presented an overview of the consensus process for developing the core domain set for psoriasis, including previous literature reviews, nominal group exercises, and meeting discussions. Future plans include the development of working groups to review candidate measures for at least 2 of the domains, including primary pathophysiologic manifestations and patient-reported outcomes, and Delphi surveys to gain consensus on the final psoriasis core domain set. (J Rheumatol 2017;44:701-2; doi:10.3899/jrheum.170151)

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The International Dermatology Outcome Measures (IDEOM) group is a nonprofit organization consisting of dermatologists, rheumatologists, patient research partners, methodologists, payers, pharmaceutical industry representatives, regulators, and others who have joined over the last 3 years to develop a core domain set (what should be measured) and measurement set (what instruments should be used) for psoriasis clinical trials, using Outcome Measures in Rheumatology (OMERACT) guidance[1,2,3]. At the 2016 annual meeting of the Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA), a summary of the work to date was presented.

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The Psoriatic Disease Payer Advisory Panel

The IDEOM Psoriatic Disease Payer Advisory Panel, held in January 2016, was cosponsored by the IDEOM and the National Psoriasis Foundation (NPF)[4]. The meeting convened patients, physicians, payers, and pharmaceutical industry representatives to discuss their perspectives on unmet needs as they pertain to outcome measures and clinical trials. Emphasis was placed on patient and payer testimonies[1]. Patients explained the effect of psoriatic disease on all aspects of their lives and how biologic therapies, in particular, have dramatically improved their quality of life; however, they also shared their frustration with barriers to access to those therapies, particularly related to economic realities of insurance coverage. Payers expressed the need for universally, clinically meaningful, published outcome measures endorsed by professional societies, which are useful and potentially mandated in clinical practice. Payers want outcome measures that help determine risk/benefit aspects of psoriasis therapies, as well as measures that can assess decreased costs related to treatment interventions, such as measures of productivity.

The IDEOM 2016 Annual Meeting and Delphi Survey

The development of a psoriasis core outcome set for clinical trials began in January 2013. To date, the IDEOM has performed a systematic literature review, face-to-face nominal group discussions, and a preliminary Delphi survey to generate a list of 193 candidate items (what can and should be measured) that was conceptually distilled to 20 candidate domains. An initial Delphi survey performed in 2014 was felt to be insufficient to generate consensus on the core domains;

therefore, a new Delphi survey was conducted in October–December 2015. The Delphi survey was sent to 300 healthcare professionals, and a similar but patient-friendly version was sent to patients partnered with both the IDEOM and the NPF. Results are pending and will be published separately.

Even though the development of the core domain set is ongoing, the IDEOM group agreed, based on audience response system voting and discussion, that work on the evaluation and selection of the instruments ("measurement sets" per OMERACT) could begin for primary skin manifestations, patient-reported symptoms, and health-related quality of life. Similar to the GRAPPA-OMERACT PsA working group, it is anticipated that this will include an assessment of the validity and reliability of available instruments. This assessment began prior to the October 2016 meeting, and the discussion continued during the meeting. A second round of Delphi is planned for ongoing development of the core domain set.

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