

The International Dermatology Outcome Measures Group: Update from the GRAPPA 2014 Annual Meeting

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ABSTRACT. The International Dermatology Outcome Measures (IDEOM) group was formed to enhance outcomes and facilitate access to dermatologic care by creating standardized measures of disease progression and treatment efficacy that emphasize the perspectives of patients and the others involved. With these goals in mind, IDEOM enabled patients, physicians, health economists from participating pharmaceutical industries, payers, and regulatory agencies to create validated measures for use in both clinical trials and clinical practice. (J Rheumatol 2015;42:1027–8; doi:10.3899/jrheum.150124)

Key Indexing Terms:

PSORIASIS IDEOM OMERACT OUTCOME MEASURES DERMATOLOGY

The first IDEOM meeting took place in Boston, Massachusetts, USA, in January 2013¹. Thirty-five members chose to begin with an evaluation of psoriasis based on its prevalence, lack of outcome measures, and increasing number of available treatments. Psoriasis is often undertreated, with up to 50% of patients with severe disease receiving only topical therapies². Current outcome measures tend to neglect the patients' perspectives and are either too complex for use in the clinic or overly reductive, and lack truth, discrimination, and feasibility.

IDEOM's structure derives from its rheumatology counterpart, OMERACT (Outcome Measures in Rheumatology). The first IDEOM meeting established categories in which to organize the components of disease to be evaluated, with discussion centering on which disease components of psoriasis were essential for inclusion in the outcome measure. These included disease characteristics necessary for diagnosis, treatment, and management. Rheumatologist mentors from OMERACT helped guide discussion among dermatologists, patients, pharmaceutical scientists, and payers. Once candidate domains were established, the first of a multiround Delphi process was initiated to form a consensus regarding the relative importance of each of the brainstormed concepts³. Based on the methodology used by OMERACT, an "onion model" was applied, which, when completed, will include a central core of essential components, a middle ring of factors of undetermined significance, and an outer ring for future directions⁴.

Using an anonymous e-mail survey, the first Delphi questionnaire was distributed to 155 participants in May 2013. Recipients included 138 experts — dermatologists, rheumatologists, payers, regulators, and industry partners, along with 17 patients. The Delphi exercise required participants to categorize items as "very important," "maybe important," or "not important." Eighty invitees responded, for a 51.6% response rate. The second meeting took place in July 2013 in Toronto, Canada, at which the results of this Delphi exercise were discussed. Attendees voted to maintain items that otherwise would have been eliminated based on low Delphi score⁵. Subsequently, items were categorized into 21 element groupings. The second Delphi exercise required 208 members to assign weight according to importance of the 21 elements. Responses came from 102 participants representing 8 countries. Again, the group included patients, providers, pharmaceutical scientists, researchers, and professional associations.

The most recent IDEOM conference took place in Rome, Italy, in April 2014. Fifty-one participants discussed the results of the second Delphi exercise. The highest scoring domains — those that were most heavily weighted based on assigned points and therefore deemed most important — were psoriasis morphology, location and area, and psoriatic arthritis (PsA). Discussion highlighted a current deficiency in determining the morphological extent of psoriatic disease, for example erosions, pustules, and fissures. Involvement of nails and intertriginous areas was felt to be similarly under-acknowledged. Location rather than extent of body surface area (BSA) was discussed, with patients agreeing that visibility is often more significant than total BSA. For a tool to reflect this, greater weighting should be placed on plaques of the face, distal arms, and hands. This reasoning has been recognized in the literature⁶. Additionally, the group agreed that the outcome measure they were creating should be appli-

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cable in both research and clinical practice. Members also noted that the effect of PsA, particularly loss of independence and functional disability, was inadequately measured in psoriasis trials, and that many dermatologists fail to screen for PsA in practice⁷. Finally, the group proposed that symptoms of psoriasis, including itch, joint inflexibility due to thickness of plaques, and skin pain need to be better represented.

IDEOM members presented their process and results at the Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA) 2014 annual meeting⁸. Since the last IDEOM meeting, patients and physicians have stratified elements into categories of pathophysiological manifestations, adverse events, life impact, death, resource use/economic impact, and contextual factors. In an effort to recruit more patient members, the group will focus on international outreach efforts. The next Delphi exercise is planned for 2015 and the next IDEOM meeting will take place in Washington, DC, USA, in February 2015.

REFERENCES

1. Gottlieb AB, Swerlick R. IDEOM: International Dermatology Outcomes Measures: a call to action. *Psoriasis Forum* 2014; 19:107-9.
2. Horn EJ, Fox KM, Patel V, Chiou CF, Dann F, Lebwohl M. Are patients with psoriasis undertreated? Results of National Psoriasis Foundation survey. *J Am Acad Dermatol* 2007;57:957-62.
3. Boers M, Brooks P, Strand CV, Tugwell P. The OMERACT filter for Outcome Measures in Rheumatology. *J Rheumatol* 1998;25:198-9.
4. Mease PJ, Clauw DJ, Christensen R, Crofford LJ, Gendreau RM, Martin SA, et al. Toward development of a fibromyalgia responder index and disease activity score: OMERACT module update. *J Rheumatol* 2011;38:1487-95.
5. Gottlieb AB, Armstrong AW, Christensen R, Garg A, Duffin KC, Boehncke WH, et al. The International Dermatology Outcome Measures initiative as applied to psoriatic disease outcomes: a report from the GRAPPA 2013 meeting. *J Rheumatol* 2014;41:1227-9.
6. Heredi E, Rencz F, Balogh O, Gulacsi L, Herszenyi K, Hollo P, et al. Exploring the relationship between EQ-5D, DLQI and PASI, and mapping EQ-5D utilities: a cross-sectional study in psoriasis from Hungary. *Eur J Health Econ* 2014;15 Suppl 1:S111-9.
7. Kimball AB, Guerin A, Tsaneva M, Yu AP, Wu EQ, Gupta SR, et al. Economic burden of comorbidities in patients with psoriasis is substantial. *J Eur Acad Dermatol Venereol* 2011;25:157-63.
8. Gottlieb AB, Levin AA, Armstrong AW, Abernethy A, Duffin KC, Bhushan R, et al. The International Dermatology Outcome Measures Group: formation of patient-centered outcome measures in dermatology. *J Am Acad Dermatol* 2015;72:345-8.