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2015 IDEOM AUGUST NEWSLETTER

International Dermatology Outcome Measures

Alice Gottlieb, MD, PhD – IDEOM Founder and Chair

The International Dermatology Outcome Measures Group (IDEOM) is a nonprofit organization founded in 2013 in order to establish standardized, validated patient-centered outcomes that are useful in both the clinic and research setting for patients with dermatological disease, with an initial focus on psoriasis and the second disease focus is hidradenitis suppurativa (HS). IDEOM brings together all the key players in one place, including patients, physicians, researchers, payers, health economists, non-profits, pharmaceutical industry members, and regulatory agencies, to create effective dermatologic outcome measures. These measures would accurately measure disease severity and reflect patient perspectives, with a goal of ultimately improving access to care and treatment options.

At the first meeting in January 2013 in Boston, MA, the need for patient input for psoriasis outcome measures was recognized. Following the Outcome Measures in Rheumatology (OMERACT) model, a preliminary list of items and domains (signs and symptoms of the disease which the stakeholders felt should be measured as outcomes) for psoriasis was composed. Afterwards, the first Delphi survey was administered. The Delphi survey is a multistep technique used to form consensus or agreement among a group of experts. Patients have been involved from the onset (in addition to the other stakeholders such as health care providers, regulatory authorities, pharmaceutical companies, the National Psoriasis Foundation, ADIPSO, IFPA, American Academy of Dermatology, Advancing Innovation in Dermatology, researchers). Two patients attended the first meeting, and 17 patients completed the first Delphi survey. The results of the first Delphi survey were discussed at the second meeting in July 2013 in Toronto, Canada. Discussion was also held about how different items related to each other, and a list of 21 domains was proposed. The second Delphi survey was administered to weigh the importance of these domains. Five patients attended the second meeting, and 12 patients completed the second Delphi survey. The results of the second Delphi survey were discussed at the third meeting in April 2014, in Rome, Italy, which was attended by 7 patients and 1 caregiver. The domains of psoriatic arthritis signs and symptoms, location and area of involvement, and primary morphology of psoriasis (i.e. what does it look like and how extensive is the disease coverage) were statistically weighted the most important based on the results of the second Delphi survey. At the fourth meeting in February 2015 in Washington D.C., extensive discussion and voting occurred to draft a core set of domains that were felt to be representative and all-encompassing. The next Delphi survey will vote on this draft core set of domains to determine the final set. The Dermatology Division leader from the U.S. Food and Drug Administration (FDA) spoke at this meeting along with speakers representing Medicare and various groups interested in measuring the quality of healthcare, in addition to 8 patient members who presented as a patient expert panel.

Patient input is essential for IDEOM to thrive and be successful, and to understand many factors, including but not limited to the impact of disease, quality of life, and treatment considerations. IDEOM's mission statement reflects these ideals: "To establish patient-centered measurements to enhance research and treatment for those with dermatologic disease."

The 2016 meeting will take place on Wednesday, March 2, 2016 at the

THE WESTIN WASHINGTON, D.C. CITY CENTER, 1400 M Street Northwest, Washington, D.C. 20005

<http://www.westinwashingtondcccitcenter.com>

Please stay tuned for more details to come.

Building Consensus on What to Measure in Psoriasis: A Look at the "Delphi" Exercise

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IDEOM's Mission

April Armstrong, MD, MPH

If someone were to ask “What is really important to measure in psoriasis?”, the answer is likely going to be different depending on who is asked. For example, a patient who has 30% of her body covered with psoriasis experiences psoriasis differently from an epidemiology researcher who examines the effect of psoriasis on a population-level. How do we bring these divergent perspectives together to attempt to achieve consensus? A formalized process of achieving consensus that is based on anonymous, iterative, and reflective principles is called the “Delphi” process, and this is the process that IDEOM is using to answer the big questions in psoriasis.

One key ongoing effort by IDEOM is to achieve consensus through the Delphi process among the various stakeholders in identifying what is important to measure in psoriasis. Answering this question accurately and comprehensively in psoriasis has wide implications. This will allow us to accurately capture the burden of disease, determine the magnitude of the burden, and evaluate how effective drugs or devices are in reducing the disease burden.

How is IDEOM tackling this key question? At this time, we are focusing our effort on answering this question for clinical trials in psoriasis. First, we are in the process of determining what should be measured in all psoriasis clinical trials. Second, we will determine what instruments will be used to measure these important aspects in clinical trials. Once we have completed this effort for clinical trials, we will tackle this key question for clinical practice. In order to ensure that we capture all the relevant stakeholders, we are engaging patients, patient advocates, physicians, pharmaceutical industry representatives, and others in this process. The results of the Delphi will be highly informative, and we look forward to sharing those with you soon!

Development of the Core Set of Patient-Centered Outcome Measures in Hidradenitis Suppurativa

While IDEOM's initial focus is psoriasis, the second disease focus is hidradenitis suppurativa (HS). IDEOM has already begun the planning stages of the creation of a HS working group. The goal is to develop a core set of patient-centered outcome measures in Hidradenitis Suppurativa through the alignment of relevant stakeholders with the goals of supporting clinical decision making at the point of care and of identifying which therapies add value in its treatment. The core group has already held one conferenced call and will hold its first in person meeting in Washington, DC on March 2, 2016.

Dermatology Innovation

William Ju, MD

President and a Founding Trustee – Advancing Innovation in Dermatology

The work by IDEOM to develop and refine outcome measures is hugely important for dermatology innovation. Product development is complex, risky, and expensive. For a product to be successful after a large investment of time and money, it must be of value to multiple stakeholders, who include patients, patient advocates, healthcare providers, investors, developers and manufacturers in industry, regulatory agencies, payers, policy makers, and others. The existence of validated endpoints that meaningfully quantify what a product does for health improvement enables and encourages these stakeholders to invest, develop, approve, produce, prescribe, use, and pay for these products. Inversely, a lack of meaningful outcome measures has a significant deterring and discouraging effect. Thus, the work of IDEOM very importantly supports the flow of impactful innovative solutions for addressing unmet needs in dermatology.

- To establish patient-centered measurements to enhance research and treatment for those with dermatologic disease

- Perspectives of patients, health economists, payers, physicians and regulatory agencies are included from the onset

- IDEOM's goal is to establish validated and standardized outcome measures that satisfy the needs of all stakeholders and can be applied to clinical research and clinical practice

CALL FOR NOMINATIONS – PATIENT BOARD POSITION

Eligible International Dermatology Outcome Measures (IDEOM) patient stakeholders who are interested in serving on the Board of Directors shall submit a statement of interest and qualifications to IDEOM at amanda@dermoutcomes.org by **Monday, August 10, 2015**.

The IDEOM Board of Directors will elect a qualified candidate by **Monday, August 24, 2015**.

ELIGIBLE CANDIDATES SHALL:

1. Be able to attend Board Meetings via conference call (weekly or bi-weekly during busy peak times)
2. Be able to demonstrate leadership
3. Be able to assist with the planning and review of the DELPHI
4. Have an analytical and strategic thinking approach
5. Have a record of service with active similar involvement
6. Must be fluent in English (read, write, conversational)
7. Have internet and access to phone with unlimited nationwide calling

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