The Journal of Rheumatology 2024;51 Suppl 2:16–8
doi:10.3899/jrheum.2024-0327
First Release July 15 2024

The Journal of Rheumatology

Report of the IDEOM Meeting Adjacent to the GRAPPA 2023 Annual Meeting

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ABSTRACT. The nonprofit organization International Dermatology Outcome Measures (IDEOM) is committed to improving the implementation of patient-centered outcome measures in dermatologic disease. At a conference adjacent to the Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA) 2023 annual meeting, the IDEOM Psoriatic Disease Workgroup presented updates on recent efforts in outcome measure advancement. Dr. Alice Gottlieb presented the preliminary findings of a study within the Mount Sinai Health System that aims to determine how well the IDEOM musculoskeletal (MSK) symptom framework, which uses the Psoriasis Epidemiology Screening Tool (PEST) and the Psoriatic Arthritis Impact of Disease (PsAID) instruments, functions in clinical settings. Drs. Joseph Merola and Lourdes Perez-Chada updated attendees on the IDEOM MSK-Q, a 9-item patient-reported questionnaire designed to measure the intensity and impact of MSK symptoms on the quality of life in patients with psoriasis (PsO) with or without psoriatic arthritis (PsA). Dr. Vibeke Strand summarized the Outcome Measures in Rheumatology (OMERACT) 2023 conference sessions. Dr. April Armstrong discussed the preliminary findings of a multicentered study designed to validate the 7-item Dermatology Treatment Satisfaction Instrument (DermSat-7) among patients with PsO. She also introduced the Psoriasis and Psoriatic Arthritis Treatment Satisfaction Instrument, a tool that seeks to capture the level of patient satisfaction with current therapy for PsO and PsA. This report summarizes the developments discussed at the IDEOM PsO and PsA research workgroups during the GRAPPA 2023 annual meeting.

Key Indexing Terms: dermatology, GRAPPA, outcome assessment, psoriasis, psoriatic arthritis, rheumatology

As part of the supplement series GRAPPA 2023, this report was reviewed internally and approved by the Guest Editors for integrity, accuracy, and consistency with scientific and ethical standards.

This work was supported by International Dermatology Outcome Measures (IDEOM). AJZ receives funding from a National Institutes of Health (NIH) research training grant (T32; T32TR004418). This project was indirectly supported by the NIH National Center for Advancing Translational Sciences. The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH.

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LMPC has received grant funding from GRAPPA and honoraria from IDEOM. VS has served as a consultant for AbbVie, Alpine Immune Sciences, Alumis, Amgen, Aria, AstraZeneca, Atom Biosciences, Bayer, Blackrock, BMS, Boehringer Ingelheim, Celltrion, Citryll, Equillium, Ermium, Fortress Biotech, Genentech/Roche, Gilead, GSK, Horizon, Ichnos, Inmedix, Janssen, Kiniksa, Lilly, Merck, Novartis, Omeros, Pfizer, R-Pharm, RAPT, Regneron, Samsung, Sandoz, Sanofi, Scipher, Setpoint, Sorrento, Spherix, and Urica. JFM is a consultant and/or investigator for Amgen, AstraZeneca, Boehringer Ingelheim, BMS, AbbVie, Dermavant, Eli Lilly, Incyte, Novartis, Janssen, UCB, Sanofi-Regeneron, Sun Pharma, Biogen, Pfizer, and Leo Pharma. AWA has served as a research investigator, scientific adviser, or speaker to AbbVie, Almirall, Arcutis, ASLAN, Beiersdorf, BI, BMS, EPI, Incyte, Leo, UCB, Janssen, Lilly, Mindera, Nimbus, Novartis, Ortho Dermatologics, Sun, Dermavant, Dermira, Sanofi, Regeneron, and Pfizer. ABG has received honoraria as an advisory board member, nonpromotional speaker or consultant for Almirall, Amgen, AnaptysBio, Avotres Therapeutics, Boehringer Ingelheim, BMS, Dice Therapeutics, Eli Lilly, Janssen, Novartis, Sanofi, UCB, and XBiotech (stock options for a rheumatoid arthritis project); and research/educational grants from AnaptysBio, Moonlake Immunotherapeutics, AG, Novartis, BMS, and UCB; all funds go to the Icahn School of Medicine at Mount Sinai. GDB, DY, and AJZ declare no conflicts of interest relevant to this article.

This paper does not require institutional review board approval.

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Accepted for publication March 25, 2024.

Introduction

The International Dermatology Outcome Measures (IDEOM) initiative, a nonprofit organization founded in 2013, is dedicated to establishing validated and standardized patient-centered outcome measures within the field of dermatology. IDEOM's mission is to enhance dermatologic research and treatment by developing inclusive, cost-free outcome measures that are readily accessible and cater to the needs of patients, physicians, government bodies, industry, nonprofit organizations, and research stakeholders.

During the IDEOM meeting, adjacent to the Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA) 2023 annual meeting in Dublin, Ireland, leaders provided updates on their progress in outcome metrics for psoriatic disease (PsD). IDEOM is actively supporting various initiatives aimed at advancing outcome measurement development, not only for psoriasis (PsO) and psoriatic arthritis (PsA), but also for conditions such as hidradenitis suppurativa, cutaneous T cell lymphoma, itch, vitiligo, alopecia areata, and actinic keratoses.

This report summarizes the updates from the IDEOM Psoriatic Disease Workgroup presented at the IDEOM meeting adjacent to the GRAPPA 2023 annual meeting.

Screening and treating-to-target for PsA

Dr. Alice Gottlieb presented the preliminary findings of an ongoing study employing the Psoriasis Epidemiology Screening Tool (PEST) and Psoriatic Arthritis Impact of Disease (PsAID) questionnaires for PsA screening and treating-to-target in real-world clinical environments.

PsA develops in up to one-third of patients with psoriasis (PsO) and goes undiagnosed in up to 41% of these patients.[1] Timely treatment of PsA is crucial, as radiological damage occurs in a significant proportion of patients at a median interval of 2 years.[2] Since PsO can precede PsA by 10 to 12 years and early initiation of treatment can prevent significant disability in patients, it is paramount that dermatologists have the tools to recognize and treat PsA in its early stages.

To address this need, Dr. Gottlieb implemented IDEOM's musculoskeletal (MSK) symptom framework[3] in the Mount Sinai Health System to screen for MSK symptoms in patients with PsO and assess PsA treatment efficacy. This screening and treatment algorithm is based on outcomes from the open panel discussion at the IDEOM and GRAPPA 2020 annual meetings. Under this schema, patients with PsO first complete the PEST, a validated instrument for PsA screening, online by MyChart (Epic Systems) before their clinic appointments. Patients scoring ≥ 3 on the PEST or those previously diagnosed with PsA by a rheumatologist further complete the 12-item PsAID (PsAID-12) on MyChart, gauging MSK symptoms specific to PsA.

Within IDEOM's MSK symptom framework, real-time data from the PEST and PsAID-12 are integrated into Epic (Epic Systems), an electronic health record system. If a patient's PEST score is ≥ 3, Epic notifies the provider, facilitating appropriate diagnostic assessments. The PsAID-12, characterized by a validated cut-off for patient acceptable symptom state (PASS), aids in evaluating the effect of treatment on PsA-related symptoms and disease burden.[4] A PsAID-12 score of ≤ 4 signifies an acceptable symptom state, supporting the continuation of the current treatment plan. Conversely, a PsAID-12 score exceeding 4 designates an unacceptable symptom state, prompting healthcare providers to contemplate treatment modification or referral. Thus, the dermatologist employs the PEST for PsA screening within our algorithm and employs the PsAID-12 to assess PsA treatment efficacy, guiding management decisions.

Between October 15, 2022, and June 12, 2023, dermatology providers at Mount Sinai encountered 2682 patients with PsO, 874 of whom participated in IDEOM's MSK symptom framework. During this period, approximately 60% of PEST-positive patients exhibited an acceptable PsAID score (≤ 4), signifying adequate management. Conversely, 40% of these patients displayed an unacceptable PsAID score (> 4), implying the need for treatment adjustment and potential rheumatology referral. These results underscore the efficacy of the PEST and PsAID-12 as patient-centered tools for PsA screening and targeted treatment strategies in real-world clinical scenarios.

Development and validation of the IDEOM MSK-Q

Drs. Lourdes Perez-Chada and Joseph Merola presented their work on the IDEOM MSK Questionnaire (IDEOM MSK-Q), an innovative instrument crafted to assess MSK symptoms in patients with PsO, regardless of diagnosed PsA. Dr. Merola started the presentation by reviewing the IDEOM PsO core domain set, which includes the measurement of PsA symptoms and the challenges around the measurement of PsA symptoms in the context of a PsO clinical study. He then explained how such challenges led to the development of an instrument to measure MSK symptoms in PsD—the IDEOM MSK-Q. Finally, he highlighted the potential benefits of measuring MSK symptoms among patients with PsO including the detection of patients with PsO transitioning to PsA.

Following this introduction, Dr. Perez-Chada delved into the development and validation of the IDEOM MSK-Q, a 9-item questionnaire for patients with PsO that aims to capture the intensity of MSK symptoms and their impact on quality of life. She shared compelling findings from validation studies for the IDEOM MSK-Q, which examined content validity, known-groups validity, and construct validity. Dr. Perez-Chada emphasized the potential for the IDEOM MSK-Q to provide insight into the transition from PsO to PsA. Various clinical studies are currently using the IDEOM MSK-Q, including Cohort for Psoriasis and Psoriatic Arthritis Registry (COPPAR) and the Preventing Arthritis in a Multi-Center Psoriasis At-Risk Cohort (PAMPA) trial. These initiatives underscore the instrument's role in advancing our understanding of MSK symptoms in patients with PsO.

Summary of proceedings of Outcome Measures in Rheumatology 2023 conference

Dr. Vibeke Strand presented a comprehensive overview of the developments discussed at the Outcome Measures in Rheumatology (OMERACT) 2023 conference. She introduced

the new OMERACT structure, which fosters collaboration and inclusivity among diverse patients, researchers, and industry stakeholders. Dr. Strand highlighted the 40 dedicated working groups whose initiatives were central to this conference's success.

During the methodology workshop, OMERACT attendees concentrated on 5 frequently selected domains in rheumatologic disease: pain intensity, pain interference, fatigue, physical function, and health-related quality of life. They aimed to establish universally agreed-upon definitions, accelerating the domain and instrument selection process. The discussion on chronic pain was particularly noteworthy and examined the complex origins of pain. A contemporary viewpoint considers 3 sources of chronic pain: peripheral (nociceptive) input, neuropathic input, and central (nociplastic) input. Dr. Strand emphasized that although we tend to place diseases in specific pain categories, chronic pain is a multifaceted experience. She highlighted the significant influence of central neuronal factors on interindividual differences in pain sensitivity. This concept challenges the previous notion that central influences are primarily psychological. During subsequent OMERACT discussions, experts delved into the intricacies of domain selection, the determination of domain weightings, and the validation process under the OMERACT Filter 2.2.

In addition to these discussions, the OMERACT 2023 conference featured enlightening special interest group sessions. These special interest groups explored particular aspects of rheumatologic outcomes research, including immune-related adverse events, safety domains, shared decision making, and specific rheumatologic conditions such as Sjogren syndrome and systemic sclerosis (SSc). Notable discussions included the development of core domain sets for Raynaud phenomenon and digital ulcers in SSc. The Contextual Factors Working Group defined the types of contextual factors and aimed to create a generic set of critical contextual factors. Speakers highlighted the need for updates in systemic lupus erythematosus core domain sets and addressed antineutrophil cytoplasmic antibody–associated vasculitis and Behçet syndrome, focusing on response criteria and defining minimal disease activity for mucocutaneous manifestations. Additionally, stakeholders discussed the following medication adherence domains: adherence, adherence phases, health outcomes, core outcomes for specific conditions, and medication-related adverse effects.

The OMERACT 2023 conference highlighted significant advancements in rheumatology outcome measures, promoting collaboration among researchers, patients, and industry experts.

Treatment satisfaction

Dr. April Armstrong presented the design and preliminary results of a multicentered cross-sectional pilot study to validate the 7-item Dermatology Treatment Satisfaction Instrument (DermSat-7) for patients with PsO. The DermSat-7 assesses the efficacy and convenience of a patient's current treatment for dermatologic disease.

On day 1 of the study, patients completed the following questionnaires via REDCap: the 9-item Treatment Satisfaction Questionnaire for Medication (TSQM-9), the Dermatology Quality of Life Index (DLQI), the DermSat-7, and a self-reported patient global assessment (PtGA). The investigator reported each participant's PtGA, Psoriasis Area and Severity Index (PASI), and body surface area. On day 14 of the study, subjects recompleted the DermSat-7 and self-reported PtGA.

The study adhered to Consensus-based Standards for the Selection of Health Measurement Instruments (COSMIN) taxonomy of measurement properties, focusing on validity, reliability, and responsiveness. The preliminary results demonstrated the instrument's ability to measure treatment satisfaction effectively among patients with PsO.

IDEOM leaders are currently working to adapt the TSQM-9 to reflect the experience of patients with both PsO and PsA.

Conclusion

In conclusion, the updates presented at the GRAPPA 2023 annual meeting by the IDEOM Psoriatic Disease Workgroup leaders reflect the organization's dedication to enhancing patient-centered outcome measures in dermatologic and rheumatologic diseases. As we anticipate further updates at the IDEOM 2024 annual meeting, it is evident that these advancements will continue to shape dermatologic research and patient care, paving the way for a more patient-centered approach in the field.

ACKNOWLEDGMENT

We thank DerMEDit (www.dermedit.com) for editing services in preparation of this manuscript.

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