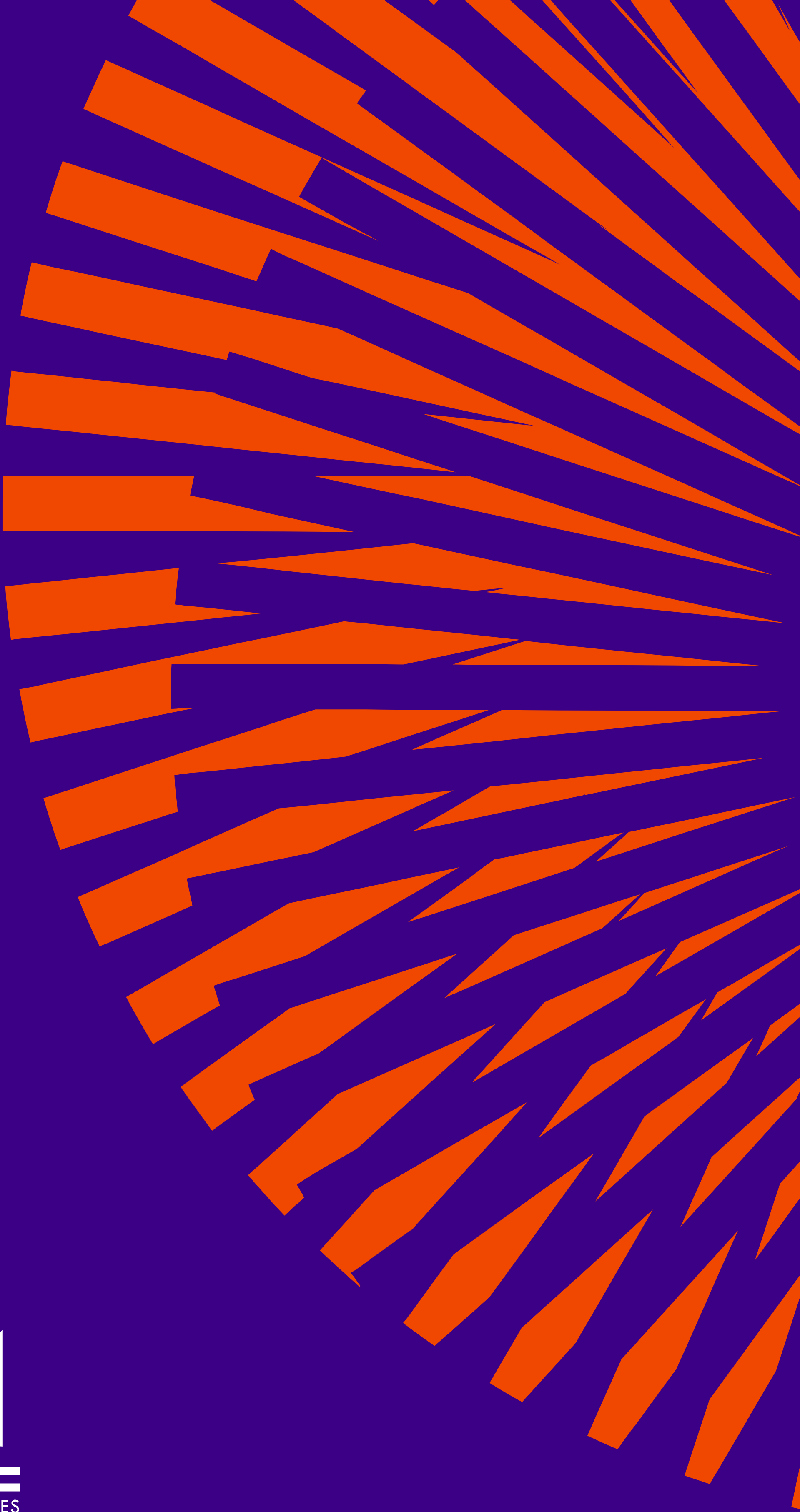
IFPA
GLOBAL LEADER IN FIGHTING
PSORIATIC DISEASE



IDEOM
INTERNATIONAL DERMATOLOGY OUTCOME MEASURES

meeting report

Washington DC
27-28th of June, 2025

Summary of Activities

IDEOM annual meeting was held in Washington DC between the 27-28th of June, 2025. One member of the IFPA secretariat, Raquel Vaz, attended the meeting, and presented a poster on the work done in 2024 on the Family Well-being project, called: Expanding the Psoriatic Disease Paradigm: Quantifying the Impact on Family Well-being Through the "Greater Patient" Lens. By attending the meeting, Raquel was able to represent the psoriatic disease community, reinforcing the need to participate in this type of events.

According to IDEOM, the meeting was attended by **physicians (28%)**, **Patient Research Partners or PRPs (20%)**, **industry (16%)**, **medical students (11%)**, **caregivers (8%)**, **non-profit (6%)**, and **government, resident or fellows, researchers and patient administration (less than 5%, each)**. The strong participation of PRPs shows the focus of the meeting, which will be described in more detail below.

IDEOM does not only have representatives of psoriatic disease, but also hidradenitis suppurativa, vitiligo, itch, actinic keratosis, acne, cutaneous T-cell lymphoma, and connective tissue diseases. This year there was also a focus on the group geriatric.

Day 1

Professor Alice Gottlieb, the president of IDEOM, welcomed the attendees and presented the mission of the working group:

- Establish patient-centered measurements to enhance research and treatment for those with dermatologic diseases.
- Include from the onset the perspective of patients, health economists, payers, non-profits, physicians and regulatory agencies.
- Establish validated and standardized outcome measures that satisfy the needs of all stakeholders and can be applied to clinical research and clinical practice.
- Provide the outcome measures for free and for all to use.

A brief mention of the updates since last year were presented, and included:

- The use of the IDEOM MSK-Q instrument in pharma-sponsored clinical trials and/or in the NPF registry.
- The presentation of IDEOM MSK-Q data in psoriasis, psoriatic arthritis and hidradenitis suppurativa and the associated publicaitons.
- Mention of the multiple manuscripts submitted and accepted from the workgroups.
- The inclusion of an itch measuring instrument in the assessment of lupus.

Following the opening session, **Dr. Jane Yoo**, a clinical assistant professor from New York presented a very interesting talk in:

Form data to action: improving clinical trial diversity for Asian Americans.

In the USA, the Asian Americans represents about 7% of the population and are the fastest growing racial group as showed by a study between 2000-2019. Asian Americans are a widely diverse group, with many different ethnic groups. With that, it is important to have representative data on safety, efficacy and equity on this population to be able to understand and improve treatment efficacy and relevance, for example.

Currently, Asian Americans are frequently excluded from clinical trials, increasing the health disparities. A good example of this exclusion is seen in cancer outcomes, screening and treatment.

It was also noted that Asian Americans are also less likely to use mental health services than other groups. Jane also presented a study that showed that only 2-5% of trial participants are Asian Americans. This is due to a combination of non-inclusion in clinical trials and the fact that this racial group is less willing to participate in clinical trials than others.

The low willingness to participate in clinical trials is, to a large extend, due to the cultural differences and other barriers such as language, communication, geographical accessibility and transportation challenges, systemic changes in research, and others. Jane used the example of the book “The Spirit Catches You and You Fall Down”, by Anne Fadiman, as a good reference on health care needs to take the cultural differences into consideration when caring for people from other cultures. As a consequence of these differences, many do not trust the health care system or report a general lack of awareness of the existence of clinical trials and their potential benefits.

Jane also presented some initiatives or strategies that can help overcome the lack of inclusion of Asian Americans in clinical trials:

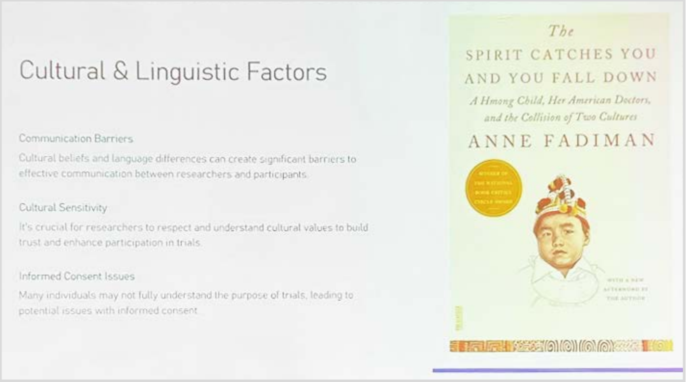
- Establish institutional review boards that can have a pivotal role in influencing clinical trials.
- Enhance outreach efforts, trust building, and tailor recruitment strategies to guarantee the diversity in these studies.
- Leverage patient navigators and members of the community working in health care on supporting the community, address concerns, and help fight for the rights of minority groups.
- Implement operational strategies that provide help, for example, with transportation challenges, language services, and giving incentives and support to increase participation. These can include vouchers for transportation, childcare services and others.

Since Asian Americans are not an homogeneous group, it is important to be aware and address the nuances between them. This is also important to consider when addressing representation and demographics.

Overall, it is pivotal to have clear and transparent communication with the community on project goals, recruitment and enrollment, and expectations.

Agenda for Discussion

- Asian American Representation in the US
- Barriers to Participation
- Regulatory & Policy Framework
- Community Engagement & Partnership Models
- Operational Strategies
- Data Collection & Reporting
- Monitoring & Accountability



Cultural & Linguistic Factors

Communication Barriers

Cultural beliefs and language differences can create significant barriers to effective communication between researchers and participants.

Cultural Sensitivity

It's crucial for researchers to respect and understand cultural values to build trust and enhance participation in trials.

Informed Consent Issues

Many individuals may not fully understand the purpose of trials, leading to potential issues with informed consent.

After this very enlightening talk, we heard the updates from the working groups.

Psoriatic Disease

Professor April Armstrong presented the work on **Treatment Satisfaction**

Treatment satisfaction is important for all diseases. It is a fundamental element of patient care, it can be used to guide treatment optimization as it can increase treatment adherence and success.

Treatment Satisfaction can be divided in three domains:

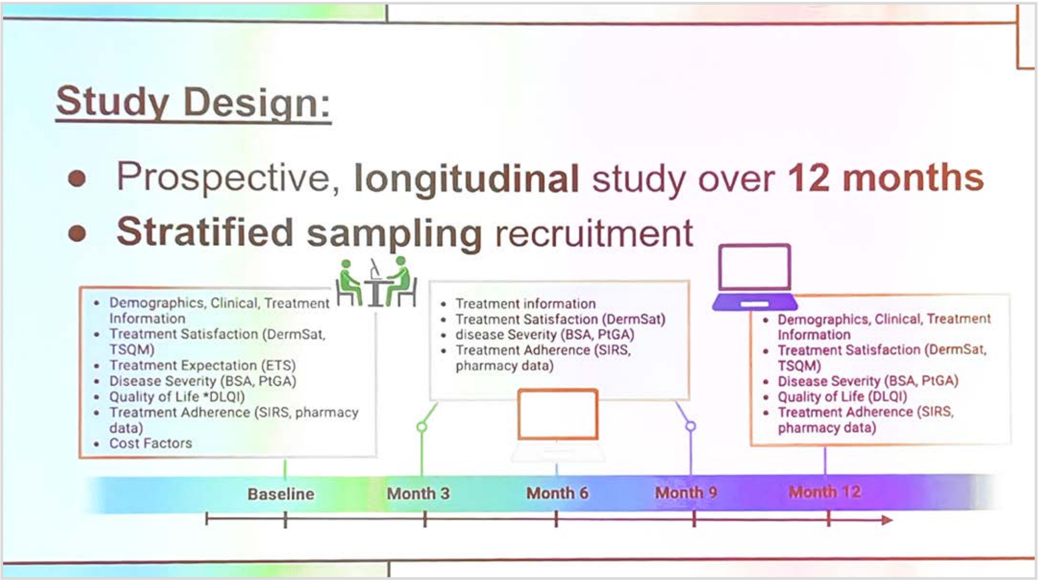
- **Effectiveness:** can it treat the skin condition; can it improve how the skin looks and feels
- **Convenience:** how is treatment stored, prepared and how does the treatment plan look like; is it easy to take or use; how often does it needs to be taken.
- **Adverse effects:** on how the skin looks or feels, effects on other parts of the body.

Cost is also a factor that affects treatment satisfaction but is usually not incorporated in the general satisfaction chart.

April also presented the validation of the DermSat-7 instrument for evaluating treatment satisfaction in people living with psoriasis and the scientific publication on the topic. DermSat-7 focuses on two main domains: effectiveness and convenience. The results showed that DermSat-7 has a high internal consistency and re-test reliability.

A sister tool, DermSat-11, that captures adverse effects domain, is also available.
This instrument is suitable for real-world studies and when perception of side effects is needed.

Dr. Peggy Chou followed and presented the ongoing study on DermSat-11.



Study Design:

- Prospective, **longitudinal** study over **12 months**
- **Stratified sampling** recruitment

- Demographics, Clinical, Treatment Information
- Treatment Satisfaction (DermSat, TSQM)
- Treatment Expectation (ETS)
- Disease Severity (BSA, PtGA)
- Quality of Life *DLQI)
- Treatment Adherence (SIRS, pharmacy data)
- Cost Factors

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This is a prospective, longitudinal study over 12 months.

Participants also participate in assessment using other instruments.

The international review board approved the use of this instrument in UCLA (University of California, Los Angeles). This study plans to recruit 200 adults with plaque psoriasis, with 121 recruited to date. To what concern the treatment breakdown, 80/80 take systemic treatment, 38/100 use topical and 3/20 are treated with light therapy.

Sarah Romanelli, a medical student from New York, presented the work on:

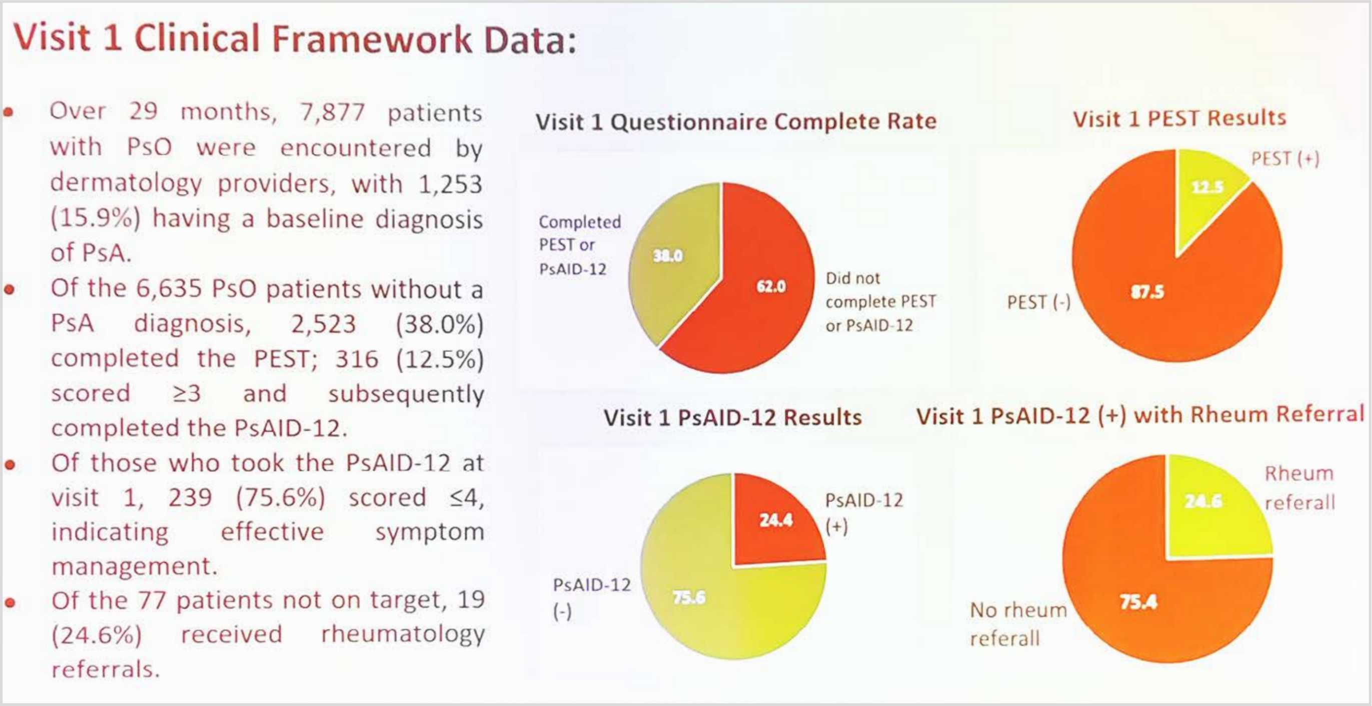
Screening and Treating to Target for Psoriatic Arthritis Using the PEST and PSAID Instrument

Is it clear that it is important to diagnose and treat psoriatic arthritis (PsA) in a timely fashion to prevent further disability. Of note, up to 41% of people living with PsA still remains undiagnosed. The majority of these are people that see dermatologists for their disease treatment (psoriasis), therefore it is on these specialists to ask and evaluate possible disease progression and joint involvement.

One possible way to increase the early diagnosis of PsA is to use instruments that predict risk. These include PEST, very useful to evaluate possible joint involvement and PSAID-12, relevant to evaluate the impact of the symptoms on the quality of life.

The goal is to integrate these two instruments into a real-world clinical setting.
Prior to the appointment with the dermatologist, patients were asked to fill out one and/or the other. Participants whose PEST score was ≥3 received the second instrument, PSAID-12 or IDEOM MSK-Q. This involves a minimal work burden for the health care provider, and it is solely for the patient to fill out. With the results from the instrument(s), e.g. with a PEST scoring ≥3 and PSAID-12 >4, there is a strong recommendation to referral for rheumatologist.

Below are the results from the study. These show that using these instruments (patient reported outcomes) is a very successful way to treat to target in a timely way.



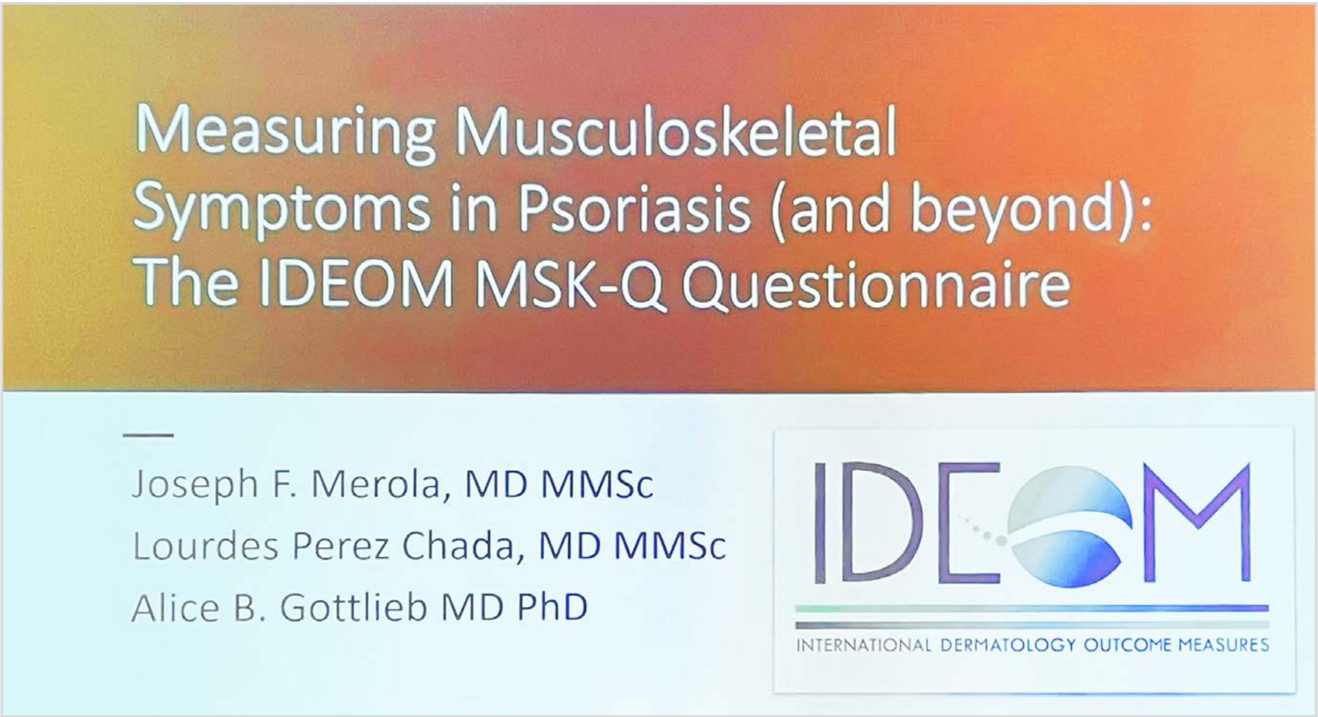
Visit 1 Clinical Framework Data:

- Over 29 months, 7,877 patients with PsO were encountered by dermatology providers, with 1,253 (15.9%) having a baseline diagnosis of PsA.
- Of the 6,635 PsO patients without a PsA diagnosis, 2,523 (38.0%) completed the PEST; 316 (12.5%) scored ≥3 and subsequently completed the PsAID-12.
- Of those who took the PsAID-12 at visit 1, 239 (75.6%) scored ≤4, indicating effective symptom management.
- Of the 77 patients not on target, 19 (24.6%) received rheumatology referrals.

The goal is to use this strategy nation-wide and even internationally.

Following Sarah’s presentation, **Dr. Lourdes Perez-Charda** presented the project:

Further Validation of the IDEOM MSK-Q for Psoriatic Disease and Next Steps



Measuring Musculoskeletal Symptoms in Psoriasis (and beyond): The IDEOM MSK-Q Questionnaire

Joseph F. Merola, MD MMSc
Lourdes Perez Chada, MD MMSc
Alice B. Gottlieb MD PhD

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Lourdes presented the consensus that 6 domains should be assessed in the instrument:

- skin manifestation
- investigator global
- psoriasis and psoriatic arthritis symptoms
- patient global
- treatment satisfaction
- health-related QoL

How to do it?

A study to evaluate the validity of the instrument was established with the following methodology: groups of people with known or unknown psoriatic arthritis were given the PEST and PSAID questionnaire for validation. For those who tested positive for PEST (scoring ≥3), the latter was given. For those who showed a positive PEST study, the IDEOM MSK-Q test was also given to test its applicability.

The PEST instrument (the Psoriasis Epidemiology Screening Tool) is a 5-question questionnaire to identify the risk of people living with psoriasis for developing psoriatic arthritis. The **PSAID instrument (the Psoriatic Arthritis Impact of Disease)** is a tool to evaluate the impact of psoriatic disease in everyday life.

The IDEOM MSK-Q instrument, tailored to evaluate the musculoskeletal symptoms, is now being used in other phase 3 and 4 trials, but it also shows its potential use in other diseases, such as HS, pustular psoriasis, etc.

Itch

Dr. Brian Kim and **Professor Sonja Ständer** presented their work on itch.

The itch working group was founded in 2021, and it is one of the most common symptoms in dermatology, making it a common pain point in all diseases covered in the IDEOM meeting.

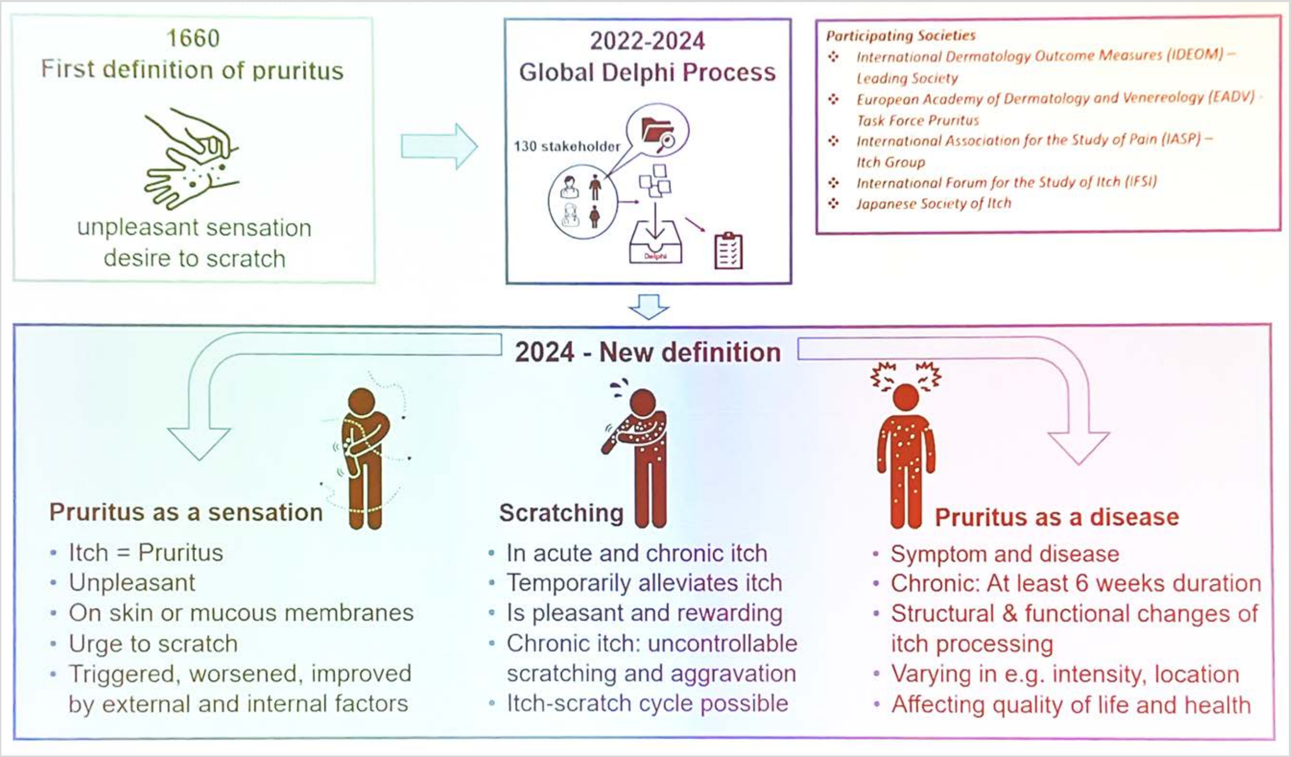
Awareness and having itch being addressed in health care is very limited, as well as what are the causes for it. It is very challenging to quantify, and the patient organization landscape is not well developed.

Goals of the working group:

- Identify barriers or recognition of chronic pruritic disorders as disease entities
- Help build pathways towards FDA approved drugs
- Enhance payer awareness, develop new metrics of clinical itch assessment, terminology, disease definition
- International Classification of Diseases (ICDs) revision along with patient involvement

Sonja presented the work on the new definition of itch and how new discussion started in 2022. The new definition, shown in image below, is now more complex, defined as a sensation and as a disease.

It was important to reinforce that itch as a disease is more than a prolonged state of an active "symptom".



1660
First definition of pruritus

unpleasant sensation
desire to scratch

2022-2024
Global Delphi Process

Participating Societies
- *International Dermatology Outcome Measures (IDEOM) – Leading Society*
- *European Academy of Dermatology and Venereology (EADV) - Task Force Pruritus*
- *International Association for the Study of Pain (IASP) – Itch Group*
- *International Forum for the Study of Itch (IFSI)*
- *Japanese Society of Itch*

2024 - New definition

Pruritus as a sensation
- Itch = Pruritus
- Unpleasant
- On skin or mucous membranes
- Urge to scratch
- Triggered, worsened, improved by external and internal factors

Scratching
- In acute and chronic itch
- Temporarily alleviates itch
- Is pleasant and rewarding
- Chronic itch: uncontrollable scratching and aggravation
- Itch-scratch cycle possible

Pruritus as a disease
- Symptom and disease
- Chronic: At least 6 weeks duration
- Structural & functional changes of itch processing
- Varying in e.g. intensity, location
- Affecting quality of life and health

It was also advertised that the first world prurigo day was celebrated on June 21st.

Geriatric

For the first time in IDEOM, we listed from **Stefano DiCenso** present the importance of addressing geriatric dermatology, or the dermatology to older people.

Current QoL tools were not built for older adults. DLQI and Skindex are more applicable to younger adults, as seen for example in questions on whether disease is affecting sport, work or school, which are not applicable for older people. The instruments also miss asking some important questions, within the domain of cognitive decline, for example, that may make it more difficult for proper care, and functional and physical limitations.

Care and support with high level of reliance for older people is on the caregivers and they also experience different social and emotional burdens.

These questions matter because they propagate a misunderstood disease burden and missed opportunities to intervein early and address unmet needs. Older people are also unrepresented in clinical trials, and they are often excluded from policy and guidelines (by not including, they exclude), the economic and social costs are often not addressed for older people, there are prevalent educational bias that exclude older people, as tools may not be accessible or usable by them.

What These Tools Miss

Cognitive & Sensory

Physical & Functional

Care & Support

Social & Emotional

With that in mind, the AGED workgroup was created in 2023, with the goal to create inclusive, evidenced-based QoL measures. As of now, they have completed a white paper about the group and the unmet needs. Next steps include developing a quality-of-life survey tool tailored for the geriatric population.

Breakout session

Following the presentations, we were grouped according to the different diseases represented at the annual meeting. The IFPA representative was in the working group for psoriatic disease and HS.

Several topics were discussed. The main ones were:

Concept of remission

How to define it? A good definition of remission is very important as it helps set a clear treatment target, guides long term disease management.

Remission can be defined as drug-free (off-treatment) or therapy (or on-treatment) remission. For drug-free remission, it is necessary that for at least one year no medicine is taken and BSA is maintained as 0 (no skin affected). On-treatment remission may be more realistic to achieve than off-treatment.

In collaboration with NPF (the National Psoriasis Foundation, USA's national organization), a DELPHI working group was established to help establishing the guidelines, which were recently published. Remission was defined when maintaining a BSA of 0 or IGA of 0 for at least 6 months while on treatment. This means that the person living with disease needs to be clear of disease for at least 6 months.

The next question that need to be discussed is how the concept of remission may affect access of care.

Other items discussed and voted on and will be the basis of the tasks to be done by the working group until the next IDEOM annual meeting.

Some items include:

- The implementation of AI in health care and as a potential tool to help report outcomes and patient experience.
- Several questions on comprehensiveness and comprehensibility of the questions in the instruments being developed.

Day 2

Patient Panel

The second day of the annual meeting started with a patient panel discussion. On the stage were two people living with HS (*hidradenitis suppurativa*), one person living with psoriatic disease and one with vitiligo.

Not only did we hear about their experience, and struggles, in receiving the right diagnosis, but also the main challenges of living with these diseases. For all members of the panel, participation in meetings like IDEOM or in clinical trials is particularly important. On the one hand, they get access to the latest information about their diseases, understand the medical jargon, how the outcome instruments are created and the science behind them. On the other hand, they become extremely knowledgeable and empowered to advocate for themselves, ask questions and demand access to the right treatments when consulting with their dermatologists.

It also became very clear how important it is to find a good specialist that sees their patients as people, not a collection of symptoms. The members of the panel also mentioned that being involved in clinical trials or having an engaging and caring specialist brings a feeling of safety and comfort, knowing that they are being taken care of.

In the case of clinical trials, having thorough documentation of the symptoms, the progress, and the burden on daily activities is helpful, not only for the people living with disease to understand the nature of the disease, but also to have it documented in the medical records.

Patient participation in the establishment of the outcome instruments is essential, as it guarantees that the right domains are being addressed and in a way that is understood by all. It is also important not to forget about all the burdens of disease, including comorbidities and the impact on mental health. Even though skin clearance may be achieved, people still feel anxiety associated with the unknown about the future. This is something dermatologists have to keep in mind.

When asked about the impact of participating in IDEOM, all panelists shared that it gave them the microphone to amplify their voices, and the presence in the annual meetings facilitated the creation of a family with the attendees. As mentioned before, the meeting creates a fantastic opportunity to learn a lot about the disease and understand what the researchers and clinicians are talking about.

Before the conclusion of the meeting, we listened to the main topics discussed in the different working groups. For some, we also voted on some points and discussed what should be on the instruments.

Following this, the annual meeting was closed.

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