

Report on the European Roundtable "Addressing Under-Prioritized Skin Diseases: Policy Responses to High-Burden Conditions" February 6, 2024

Overview and Rationale

GlobalSkin and the European Society for Dermatological Research co-hosted an online Roundtable "Addressing Under-Prioritized Skin Diseases: Policy Responses to High-Burden Conditions" on February 6, 2024. This initiative was prompted by the European Commission's 's 2023 Discussion Paper entitled "[Scoping Study on Evidence to Address High-Burden Under-Researched Medical Conditions](#)" in which "Skin and sub-cutaneous diseases" was identified as one of the 12 therapeutic areas defined as high-burden and under-researched. The event convened a diverse array of experts, policymakers, and stakeholders in the field of dermatology and public health. Speakers at the event crafted policy recommendations in response to the discussed issues.

Summary of Main Ideas

Stella Kyriakides, EU Commissioner for Health and Food Safety, emphasized the important role of GlobalSkin in advocacy and awareness for dermatology patients. Skin conditions often find themselves outside the collective awareness. In follow-up to the above-mentioned Discussion Paper, new research funding opportunities have been provided within the framework of the Health cluster of the Horizon Europe programme. Funding leverages technology, fosters collaborations and the exchange of data, informs policy makers, engages patients and improves clinical guidelines access. The Commission is determined to address the under-prioritized skin diseases and GlobalSkin plays a key role in these efforts.

Karin Veldman, patient advocate from Dutch Skin Association, outlined difficulties of living with the burden of dermatological diseases, based on her personal experience, as well as the experiences of other patients living with burdensome chronic skin diseases. The absence of thorough research and data hinders the development of effective responses and tangible solutions. Prioritizing research on mental health is imperative in this regard.

Jennifer Austin, CEO of GlobalSkin, presented on the real-world evidence on true burden of skin diseases on patients and their families, through the Global Research on the Impact of Dermatological Diseases (GRIDD) project that GlobalSkin co-leads with research partners. Based on Discussion Paper recommendations, she stated that researchers need to quantify impacts of skin diseases on patients, using tools like the new Patient-Reported Impact of Dermatological Diseases (PRIDD), which will allow understanding to expand beyond the current Global Burden of Disease data.

Matthias Augustin, Director of the Institute for Health Services Research, Professor at University Medical Center Hamburg, highlighted the economic impact of dermatological diseases in Europe, emphasizing the weight of chronic skin conditions through direct, indirect, and intangible costs. To address these challenges, several actions are necessary, including recognizing the person-centred burden of rare skin diseases; providing backing to international networks such as EURORDIS; making data-driven decisions, requiring comprehensive registry research; enforcing more rigorous disease coding practices (i.e. ICD-11); enhancing support systems for individuals affected by rare skin diseases; and improving connectivity between community healthcare and specialist care through digital platforms.

Sabine Eming, Past President of ESDR, centered her presentation on the significance of skin health in an aging society and the associated education and awareness challenges. She emphasized the importance of raising public understanding and augmenting funding to enhance not only healthcare systems but also clinical and basic research in the field.

By bringing the industry perspective to the discussion, **Tina Taube, Director Market Access & Orphan Drug Policy Lead at EFPIA**, expressed the importance of adequately defining Unmet Medical Needs in the renewed EU Pharmaceutical Legislation for sustainable health systems.

Finally, **Clément Evroux, Policy Analyst at the European Parliament Research Service** presented the EU's strategies for addressing health challenges, emphasizing the role of research policy in filling gaps. He provided insights into funding opportunities for skin health in Horizon 2020 and Horizon Europe, also addressing short- and long-term trends within the current and future financial frameworks.

Policy Recommendations for Consideration

1. Mental Health Emphasis:

- Direct priority and resources to mental health research, considering that individuals with skin diseases often endure high levels of anxiety and depression compared to others.
- Understanding the person-centred impact of rare skin diseases.

2. Awareness Campaign:

- Promote awareness of the issue, particularly concerning skin health in aging populations and the challenges related to wound healing disorders such as chronic ulcers, scarring, and fibrosis.

3. Simulating Research Initiatives:

- Encourage the establishment of extensive research networks.
- Promote researcher mobility.
- Ensure accessibility to incentives for conducting research on these medical conditions, including non-financial incentives.
- Foster the organization of specialized conferences in relevant medical fields.

4. Enhanced Funding Opportunities:

- Create improved national, EU, and international funding programs.
- Develop and implement specific funding strategies, including financial support within the healthcare system (e.g., allocating resources for wound care within health budgets), funding for clinical research (beyond pharmaceutical industry support), and support for basic research.
- Provide financial support for networks like EURORDIS.
- Involve dermatology stakeholders actively in the preparation of upcoming EU multiannual financial frameworks.

5. Addressing Unmet Medical Needs:

- Formulate a patient-centered, inclusive definition of unmet medical needs (UMN), prioritizing innovation and advancements in prevention, treatments, and care to ensure equitable access for all patients.



- Evaluate UMN comprehensively by considering patient-relevant outcomes and broader societal benefits beyond just morbidity and mortality.
- Engage stakeholders from various backgrounds to identify UMN through multi-stakeholder collaborations, involving diverse patient groups and healthcare system representatives, with clear rules of engagement.
- Initiate collaborative discussions to address challenges related to the availability, accessibility, and affordability of innovative medicines and to ensure the long-term sustainability of health systems¹.

6. Health Policy Enhancement:

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- Base health policy decisions on data-driven insights, necessitating registry research.
- Implement coding practices more rigorously (ICD-11 being much better in terms of identifying rare diseases than ICD-10).
- Provide enhanced support for individuals affected by rare skin diseases.
- Enhance the connection between community healthcare and specialist care through digital platforms.

¹ For the consolidated position of the European Patients' Forum on the revision of the EU Pharmaceutical Legislation, including Unmet Medical Needs, please refer to <https://www.eu-patient.eu/news/latest-epf-news/2023/epf-recommendations-for-the-revision-of-the-eu-pharmaceutical-legislation/>