EUROPEAN
ACADEMY OF
DERMATOLOGY &
VENEREOLOGY

EADV Policy Roundtable:
Addressing the Burden of Skin Disease in Europe through Policies and Partnerships

REPORT

Key take-aways

- EADV's Burden of Skin Disease survey, the first of its kind in Europe, reveals information about the prevalence of skin diseases, as well as factors pertaining to patient care, stigmatization, quality of life and satisfaction of the care patients receive from dermatologists.

- Nearly one in two Europeans report having suffered from at least one dermatological condition in the past twelve months. Extrapolated to the European population, around 185 million individuals are affected.

- Around 70 per cent of diseases listed in the survey severely affect the quality of life of patients. 15-20 per cent of all respondents report feelings of stigmatization and 48 per cent report being moderately or extremely anxious or depressed due to their condition. Around half of respondents find their condition quite or very embarrassing. A significant impact on patients' professional activities is evidenced by the data.

- Disparities in the dermatology workforce and differences in healthcare services across Europe imply inequalities in access to dermatological care. However, overall, a high level of satisfaction in the care provided by dermatologists is reported.

- Common misconceptions exist about skin and venereal diseases and greater awareness is needed about the severe and sometimes life-threatening nature of some conditions.

- Skin conditions are often associated with significant co-morbidities, underscoring the need for patients to be treated in a holistic way.

- Recent decades have seen impressive advances in the treatment of skin diseases. Continued research is needed as well as the evaluation of treatments provided off-label. Despite scientific advances, however, hurdles exist in patient access to certain therapies.

- Guidelines are important tools for setting standards, guiding healthcare professionals and informing patients of the treatments they are entitled to. In order to improve implementation they should be tailored to relevant audiences, with concise summaries prepared for patients and general practitioners, and disseminated widely. Patients should be involved in the development of guidelines from the outset. Better cooperation is needed between guideline developers to reduce duplication of efforts.

- While multidisciplinary care is recommended for some skin diseases, it is not systematically offered in practice. Education and awareness campaigns are required to improve awareness of the need for multidisciplinary care. Multidisciplinary consultations are cost-saving in the long-term and result in better patient experience. Multidisciplinary collaboration is needed at scientific level as well as at the level of care delivery and dermatologists should actively advocate for improved collaboration, via their national societies.

- Improved health literacy results in better-informed and empowered patients and facilitates shared decision-making, which in turn lead to better treatment compliance and patient satisfaction. There is a scarcity of patient decision aids in dermatology and of those that exist, very few meet international standards. Lessons can be learnt from palliative care, oncology and cardiology.

- There are large discrepancies in health literacy across Europe, and while dermatologists cannot be responsible for improving the health literacy of whole populations, they can be more involved in education through their own practice and activities at national level, set examples and motivate colleagues to become more active in education at regional and local levels, and take the opportunities offered by the network and education platform of EADV to enhance patients' education.

- The European Commission's Healthier Together non-communicable disease initiative includes health literacy as a key topic within its prevention theme. Furthermore, the European Commission is supporting health literacy in cancer through the revision of the European Code Against Cancer, and the sharing of best practices with a focus on disadvantaged groups.

- The World Health Organisation is producing a guide for health literacy development for non-communicable diseases and will soon launch a project to operationalize the meaningful engagement of people living with non-communicable diseases.

- Albinism is a condition that affects the hair, skin and eyes, yet when assessing a person's disability, very little attention is given to skin-related aspects of the disease, nor to their impacts on the person's quality of life. Updated disability criteria, access to genetic testing and research into albinism and skin cancer are needed to reduce the burden on patients.

- Major improvements have been made in the treatment and management of psoriasis over the past decade, thanks to initiatives and commitments of the multi-stakeholder psoriasis community. An important framework for guiding policies and collaboration in the area has been the 2012 European White Paper 'A framework for improving the quality of care for people with psoriasis' a joint project between EADV members and patient representatives. However, many patients still do not have access to treatment, or have access to topical treatments only. Several multi-stakeholder partnerships are ongoing in the field of psoriasis with the aim of producing a paradigm shift in the delivery of care.

- In the field of rare skin diseases, ERN Skin is a collaborative, cross-border initiative creating a critical mass of patients to enable the development of registries and guidelines and is an example of how pooling resources at European level can overcome the barriers faced at national level.

- Significant disparities exist across the whole spectrum of skin cancer prevention, diagnosis and care, from country to country, and even within countries. With a view to addressing cancer inequalities, the European Commission has launched a European Inequalities Registry, identifying trends, disparities and inequalities between EU Member States and regions.

- There is insufficient data on the impact of dermatological diseases on patients and current measures do not meet best practice criteria. GlobalSkin's GRIDD project will produce a new, patient-centric measure of dermatological disease burden, which aims to transform understanding of dermatological diseases. It will be used to help elevate the policy prioritization of skin diseases in healthcare systems.

- Patients organisations can help gather patient data through their networks, but data collection requires resources, which patients organizations most of the time do not possess.

- The World Health Organisation uses evidence-based information to create norms and standards in healthcare. It is currently reflecting on how to integrate dermatological diseases into people-centred primary healthcare, and clear data is essential for this process.

- Moving away from using the term 'patient engagement' and instead referring to the meaningful engagement of people living with non-communicable diseases can help unpackage patients' lived experiences, which can be integrated in the co-design of policies in order to address stigma and discrimination.

- Elevating the prioritization of skin diseases requires a multi-stakeholder approach. The Global Dermatology Coalition was launched in 2022 as a coalition for patients, dermatologists and industry to work together towards this goal on a common platform. The case for investing in skin diseases should be elaborated to include impacts on finance ministries, health sectors and educational sectors.

Welcome and Introduction

Alexander Stratigos
EADV President and Professor of Dermatology-Venereology, University of Athens Medical School

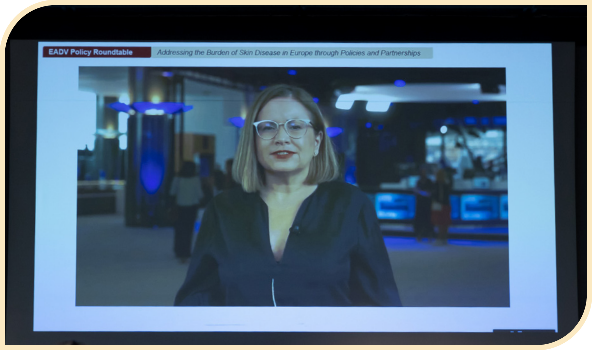
Alexander Stratigos introduced EADV's **Burden of Skin Disease survey**, undertaken in 2020-21 amongst nearly 45,000 adults from EU-27, UK, Norway and Switzerland. The largest ever study undertaken of its kind in Europe, the project reveals important data for policy-making and agenda-setting in dermatological disease management.

EADV's Policy Roundtables provide a **forum for interactive discussion** between dermatologists and the many stakeholders active in improving skin health in Europe – patients and patients organisations, policymakers, epidemiologists, health economists, industry and others.

The findings of EADV's Burden of Skin Disease survey mark the point of departure for the present Policy Roundtable, which comprises two solution-oriented sessions exploring the role of policies and partnerships in addressing the burden of skin diseases in Europe.

Video message from the European Parliament

Maria Spyraki
Member of the European Parliament, European People's Party, Greece



In a pre-recorded video statement, Member of the European Parliament (MEP), Maria Spyraki, urged **more attention to skin diseases at European level**. Skin diseases are an important public health concern that affect nearly one in two Europeans, and concerted efforts are needed to reduce the burden of these diseases on citizens.

Over the past two years, as a member of the European Parliament's Special Committee on Beating Cancer, Spyraki has worked closely with EADV to promote adequate measures on skin cancer within Europe's Beating Cancer Plan. As a result of this collaboration, the Committee's report 'Strengthening Europe in the fight against cancer: Towards a comprehensive and coordinated strategy' includes a **set of recommendations to address excessive exposure to UV radiation**, such as strengthened legislation on artificial tanning devices, actions to protect outdoor workers from harmful sun exposure and improved skin cancer registration.

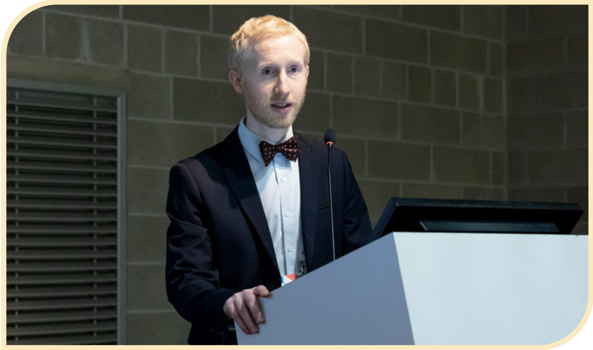
Spyraki concluded her statement with a call to take the opportunity of today's Policy Roundtable to make progress towards **transforming scientific knowledge and proposals into real change for patients**, enabling safe and timely access to specialized dermatological care, no matter where they live in Europe.

Patient Testimonial

Antoine Gliksohn
Global Albinism Alliance

Antoine Gliksohn, a person with albinism and representative of the Global Albinism Alliance, described albinism as a rare congenital genetic condition characterized by partial or complete hypopigmentation that affects the hair, skin and eyes. Lack of pigmentation leads to abnormal development of the eyes that results in mild to severe visual impairment. Gliksohn explained that there is **no treatment for albinism**, and **all people with albinism can be considered as having a disability**. In most EU countries, the degree of disability is primarily evaluated based on the person's visual acuity, whereas **very little attention is given either to skin-related aspects of the disease, or to impacts on the person's quality of life**.

Gliksohn's two siblings also have albinism, and when his elder sister was born, his parents were given the **inaccurate information** that she was blind. This misinformation, combined with a lack of psychological support, **unnecessarily increased the burden of the disease** on the family. While this specific case dates back forty years, Gliksohn explained that such **situations still occur today**.



Gliksohn described three other cases of albinism. In 2015, at the age of 24, his friend Maëlle was offered genetic testing at Bordeaux hospital in France and subsequently diagnosed with a **syndromic form** of albinism called Hermansky-Pudlak syndrome, which, along with the eye and skin symptoms of albinism, also causes symptoms affecting the lungs and blood. Such symptoms are often missed during clinical consultations, but can be life-threatening and require very specific management. In most EU countries, **most people with albinism do not yet have access to such genetic testing**.

Camille, born in 1993 in Korea, and adopted by a French family, spent every school break inside, while her schoolmates played together outside. Her parents had been advised against letting her spend time outdoors due to her albinism, meaning that while her skin was protected, her **psychosocial development and friendships were undoubtedly hindered**.

Clemence, mother of 2-year-old Achille with albinism, faces a daily battle trying to apply sun protection to her son. However, given the **lack of studies on sun protection and albinism**, there is no reliable guidance for parents on sun protection.

Gliksohn's own experience of growing up as a person with albinism was heavily marked by a **looming threat of skin cancer**. However, it is unknown whether the risk to this group is higher than light-skinned people or not due to the **lack of published studies on the prevalence of skin cancer amongst people with albinism in Europe**.

Gliksohn concluded that the best way to address albinism is to find a **treatment** to deal with all the symptoms but until that point **a lot can be done to alleviate the burden of the disease**, as highlighted in the patient cases described.

Keynote speech: The burden of skin disease in Europe

Marie-Aleth Richard
Head of Department, Dermato-oncology, Timone Hospital, Marseille
and Scientific Coordinator, EADV Burden of Skin Disease Survey

Marie-Aleth Richard, Scientific coordinator of EADV's Burden of Skin Disease survey, gave an overview of the project and its main results. The web-based online survey captured data from nearly 45,000 adults from EU-27, UK, Norway and Switzerland, and reveals information about the **prevalence of skin diseases**, as well as factors pertaining to **patient care, stigmatization, quality of life** and **satisfaction of the care patients receive** from dermatologists. It is a population-based study on representative samples of the adult population, according to age, gender, geographical location and social category.

Prevalence of skin diseases

The survey results[1] show a **very high prevalence of skin conditions** within the European population, with 43.35 per cent of respondents reporting having had **at least one dermatological disease or condition** in the previous 12 months. Projected to the European population this means around **185 million individuals are affected**.

Highest prevalence diseases are fungal skin infections, acne, atopic dermatitis/eczema, alopecia and psoriasis. Extrapolated to the European population, this means that 16-38 million individuals are affected by at least one of these conditions, with some reporting suffering from three or even four.

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1. Prevalence of most common skin diseases in Europe: a population-based study, Richard M-A et al (JEADV 2022)

Acne, vitiligo and sexually transmitted infections (STIs) affect mainly young adults and respondents over 25 years report psoriasis more often than younger adults.

Burden of disease, quality of life and stigmatization

Of conditions that cause the most disturbance to patients' lives, hair loss is the most burdensome, followed by psoriasis, varicose veins, acne and herpes.

Around 70 per cent of the diseases listed **severely affect the quality of life of patients**, with dyshidrosis (bullous eczema), STIs, hidradenitis suppurativa and alopecia exerting the highest impact on quality of life. 15-20 per cent of all respondents report **feelings of stigmatization** and some conditions are reported to have an extremely high impact on patients due to stigmatization, most notably hidradenitis suppurativa, followed by acne and vitiligo.

48 per cent of respondents report being **moderately or extremely anxious or depressed** due to their condition and high numbers suffer from tiredness, difficulty sleeping, and have insufficient time to care for themselves.

Around half of respondents find their condition **quite or very embarrassing**, with vitiligo and hidradenitis suppurativa and vitiligo scoring highest in terms of impact on personal or professional life. Around one fifth of respondents **reoriented their professional activity** due to their condition, and a similar number **adapted their working hours** due to their skin complaint. Around 1 in 6 **chose their work** with their skin condition in mind, and a similar number have **refused a job offer** due to their skin condition.

Healthcare pathway and access to care

The main request from patients seeking a consultation with a dermatologist is for a **mole check** or **skin cancer screening**. Patients were most easily able to receive such screenings in Portugal, Austria and Germany whereas they had more difficulty in some other countries.

There are **significant variations in the ratio of dermatologists to population** between different EU countries (0.12 to 7.08 per 100,000 population). In some countries, patients have **direct access** to dermatologists, while in others they must be **referred by their GP**. Waiting times for urgent care vary between zero and twelve weeks and for chronic conditions between zero and twenty-four weeks. Medical insurance is compulsory in almost all (90%) surveyed countries.

The survey results, showing disparities in the dermatology workforce and differences in healthcare services across Europe, imply **inequalities in access to dermatological care across the continent**.

Overall, a **high level of satisfaction** in the care provided by dermatologists is reported by respondents. Most consider dermatologists the experts for treating **skin cancer, acute and chronic skin diseases**, whereas they consider other healthcare professionals (e.g. gynecologists, urologists or others) the experts for treating STIs, reflecting varied organization of healthcare for STIs across Europe.

SESSION ONE
Ensuring equal access to high quality management of skin diseases

A decade of progress in managing skin diseases in Europe

Christian Vestergaard
Department of Dermatology and Venereology, Aarhus University, Denmark
and President, Nordic Dermatology Association

Christian Vestergaard introduced some **common misconceptions** about skin and venereal diseases, explaining that while many people consider dermatological conditions minor ailments, the reality of the diseases that dermatologists are confronted with are very different.

Some conditions can be **severe** (psoriasis, acne, urticaria, atopic dermatitis, hidradenitis suppurativa, bullous pemphigoid and skin cancer) and in the case of melanoma, **life-threatening**. Certain skin diseases are associated with **significant co-morbidities**, with some psoriasis patients suffering from arthritis and at risk of developing diabetes and psychiatric disease. Atopic dermatitis patients may suffer from food allergies, eosinophilic oesophagitis, asthma, cardiovascular disease, hand eczema, depression and anxiety.

Given these co-morbidities, Vestergaard explained, patients with skin diseases need to be managed in a **holistic way**.

Recent decades have seen **impressive advances** in the treatment of skin diseases, with the approval of the first biologics for psoriasis, JAK1/JAK2 inhibitors and biologics for atopic dermatitis, and photodynamic therapy. Vestergaard explained that now it is the turn of **artificial intelligence (AI)**, the new tool to help diagnose and treat skin conditions, including rare diseases.

While the science of treating skin diseases has undoubtedly made impressive progress, hurdles exist in **patient access** to certain therapies. While many treatments are currently available and reimbursed by healthcare systems, some therapies are provided off-label and are not reimbursed. Vestergaard stressed the importance nonetheless of **evaluating off-label treatments**.

He underscored the need for **continued research**, not only in therapeutics but also in diagnostics, to ensure optimal management of skin diseases.

In tandem with scientific progress, Vestergaard concluded with recommendations for tackling skin diseases, developed by a Danish patient-led multi-stakeholder alliance: ensuring **coherent treatments** between sectors and departments, creating **equal access** to treatment and **support for all patients**, a **holistic treatment approach**, and the **prevention of stigmatization**.

Panel discussion

MODERATORS

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Barry McGrath
Hidradenitis Suppurativa, Ireland

Ana-Maria Forsea
Professor of Dermatology, Carol Davila University of Medicine and Pharmacy, Romania

Matthias Augustin
Institute for Health Services Research in Dermatology and Nursing (IVDP), University Medical Center Hamburg-Eppendorf

Branka Marinovic
Co-coordinator, ERN-Skin

Donata Meroni
Head of Unit C1 'Health promotion, disease prevention, financial instruments' DG SANTE, European Commission

Danuta Marchi
Global External Engagement Lead, Immuno-dermatology Mission, UCB Biopharma

Introduction

The panel session focused on equal access to high quality treatment and care for skin disease patients in Europe. Panelists were asked to give their perspectives on the levers for enabling patients' access to the best possible care and treatment, with a particular focus on the roles of policies and partnerships.

The panel discussion was moderated by Myrto Trakatelli, Chair of EADV's Advocacy Working Group, and Alexander Stratigos, EADV President.

Guidelines

Christian Vestergaard made the distinction between **official national clinical guidelines** which are funded by the government and are legally binding, and guidelines produced by **dermatological societies**. In Denmark, national clinical guidelines exist for psoriasis only, and guidelines produced by dermatological societies are not optimally disseminated. He recommended that they be **tailored to relevant targets** including general practitioners and patients organisations (for example making them short and operational) and **disseminated widely**.

Matthias Augustin added that guidelines are a set of **standards** used to guide dermatologists and people treating patients, but they are also (in the case of official, national guidelines) a guide for payers, meaning they represent the **evidence-base** for the treatment and care that should be considered for **reimbursement** by healthcare authorities. They should be intelligible by patients themselves, enabling them to understand which **treatments they are entitled to**. As such, they must be translated into **language that is understandable** by patients, as well their general practitioners. Augustin explained that well-developed guidelines exist for some conditions but their dissemination to patients and general practitioners, and their implementation, are not sufficient. Short, synoptic guidelines that are 'living' documents and regularly reviewed, are recommended.

The role of healthcare professionals and patients' organisations in developing guidelines and fostering their implementation was discussed, with Barry McGrath explaining that a recent systematic review on eczema guidelines showed **less than 25% patient representation** or patient organization involvement. He stressed that in order for patients' organizations to buy into guidelines, and for patients to understand them, they should be **fully involved** from the very beginning. Patients can help **validate guidelines** and **identify potential problems** early on. Precedents exist for patient involvement in guideline development, such as the **EuroGuiDerm Guidelines**, which involved patients from start to finish. He added that guidelines should include **plain language summaries** that patients with average health literacy can understand. Different formats (written, visual, video) or a combination of formats can be used to make them easily digestible.

Branka Marinovic, Co-Coordinator of the European Reference Network on rare skin diseases (ERN Skin) explained that one of the goals of the ERN is to publish guidelines, with patient involvement. However, production of guidelines is expensive and many guidelines already exist, so she suggested **better cooperation** in order to not overproduce guidelines on one topic.

Multidisciplinary care

McGrath, a Hidradenitis Suppurativa (HS) patient, recalled the Burden of Skin Disease survey data which showed HS topping the graphs in several areas for its heavily negative impact on patients' quality of life. While HS is a very challenging disease to deal with physically, McGrath reiterated its devastating effect on virtually every domain of a patient's life.

European and international guidelines set out the need for **multidisciplinary care for HS patients**, who, according to McGrath, should be referred to a multidisciplinary team as soon as they receive their diagnosis, given their high rate of co-morbidities, but this does not happen in practice. McGrath explained that this is due to a **lack of awareness about the burden of skin diseases** such as HS. He recommended **education and awareness campaigns** as a means of rectifying this.

Vestergaard agreed with the value of multidisciplinary teams and that while it is more expensive for payers if patients have consultations with three or four doctors at a single visit, this approach is **cost-saving in the long-term** and will certainly result in a **better patient experience**.

Ana-Maria Forsea reminded participants that the burden of skin diseases is a **complex patchwork** across Europe, owing to the diversity of healthcare systems and socio-economic and cultural frameworks within which healthcare occurs. She stressed the need for **multidisciplinary collaboration** at the scientific level as well as at the level of care delivery, and encouraged the community to be proactive and to call for **policy change to support multidisciplinary care** in each Member State.

Health literacy

McGrath referred to data demonstrating the benefits of improved health literacy on patients, healthcare and society at large. He explained that it results in **better-informed and empowered patients** and facilitates **shared decision-making**, which in turn lead to **better treatment compliance** and **patient satisfaction**.

He highlighted the **scarcity of patient decision aids**, explaining that of the small number that have been developed in dermatology, very few meet international standards. He added that lessons can be learnt from the fields of palliative care, oncology and cardiology where such initiatives have been ongoing for several decades.

Forsea explained that the health literacy of skin disease patients is dependent on the health literacy of the population of a country at large. A recent EU report shows a **significant discrepancy in health literacy** between EU countries, with Eastern European countries, including Romania consistently lagging behind. As an example, while 50 per cent of the Romanian population do not access the internet for health information in any given year, this figure is only 12 per cent in the Netherlands and Denmark. While it is not feasible for dermatologists to improve the health literacy of an entire population, Forsea recommended that they be **more involved in education** through their own practice and activities at national level, that they set examples and motivate colleagues to become more active in education at **regional and local levels**, and take the opportunities offered by the network and education platform of EADV to enhance patients' education at national level.

Donata Meroni provided an overview of the European Commission's actions in the field of health literacy. The EU's *'Healthier Together'* non-communicable disease campaign has just been launched, which includes health literacy as one of the key topics within the prevention theme. Furthermore, Europe's Beating Cancer Plan foresees several actions to improve health literacy on cancer risks and determinants, including the forthcoming revision of the **European Code Against Cancer**. The Code, which includes recommendations for avoiding the harmful effects of sun and sunbeds, will be widely disseminated via a new mobile App for cancer prevention, which aims to reinforce awareness and empower citizens to manage their health.

Furthermore, the European Commission is supporting the development and sharing of best practices to strengthen health literacy and cancer prevention, with a focus on disadvantaged groups.

Spotlight on psoriasis

Psoriasis is an area of dermatology where **major progress has been made**, with improved technologies, greater disease awareness, the development and implementation of guidelines, investments by industry and the active participation of patient groups contributing to improved quality of life of psoriasis patients and reduced disease burden.

An important lever for advocacy and policy-shaping in the field of psoriasis was the *2012 European White Paper 'A framework for improving the quality of care for people with psoriasis'*, a joint project between EADV members and patient representatives. Ten years on, Matthias Augustin, who was a driver of the initiative congratulated the psoriasis community for making impressive progress on the goals set out in the White Paper.

Giving the industry perspective, Danuta Marchi stressed UCB's belief in the **power of partnerships** to tackle **complex unmet needs of patients**. She acknowledged the work of patient advocacy groups and their regional and national members, who have helped address the stigma associated with psoriasis as well as the social and mental health impacts of psoriasis and other skin diseases. Industry has played its part in **driving innovation** which has made the promise of rapid and long-lasting skin clearance of psoriasis a reality. However, Marchi stated that research shows the vast majority of patients in Europe either **do not have access to treatment** or **have access to topical treatments only**, meaning the goal of reducing the physical, social and mental health burden of psoriasis is still wishful thinking for many.

Marchi highlighted the potential of partnerships to change this status quo and gave two examples. Firstly, *Epicensus (Consensus and action to elevate psoriasis care)* is a UCB initiative which brings together clinicians, payers and patient group representatives to gain their insights on standard of care in psoriasis, and to develop consensus on the improvements that could be made in the psoriasis patient pathway in Europe. The ultimate goal of the project is a **paradigm shift** in the delivery of psoriasis care in Europe.

A second UCB partnership is a patient reported outcome measurement tool developed in Denmark as a partnership between patients, clinicians, the Danish PROM agency and industry. An app is being piloted to allow the continuous assessment of patient outcomes, which are then integrated into patients' health records in hospital and at primary care level.

Stratigos added that a very influential parameter in the advancement of skin disease care is **technology**, with steady improvements in this area expected to facilitate access to care and patient literacy through the use of **apps**, **e-health records** and other means.

Rare skin diseases

Branka Marinovic, Co-Coordinator of the European Reference Network (ERN) Skin described the value of European-level collaboration in the field of **rare skin diseases**. ERN Skin brings together rare skin disease experts and creates a critical mass of patients to enable the development of registries and guidelines.

Meroni explained that the ERNs are an initiative of the European Commission and were set up in 2017, further to the adoption of the **EU Cross-Border Healthcare Directive**. The creation of ERN Skin represents a major step forward in improving the quality of life of patients with rare skin disorders of all ages and is an excellent example of how pooling resources at European level can overcome the barriers faced at national level.

Skin cancer

While access to treatments is a crucial issue, Stratigos added that **access to diagnosis** should not be neglected. In the area of skin cancer, **early diagnosis is essential** to avoid preventable death.

Forsea described the **significant North-South, West-East disparities in melanoma outcomes** across Europe, with 90 per cent survival in the Nordic countries and less than 50 per cent in Bulgaria. While disease outcomes such as survival or mortality are the 'visible' part of melanoma inequalities, there are in fact **inequalities across the whole spectrum of skin cancer care**, including registration and reporting of cases, prevention and early diagnosis, as well as access to innovative treatments and survivorship care. For example, in Romania and Serbia, melanoma incidence is reported as four new cases per 100,000 per year, while in Germany this figure is twenty and in Denmark thirty, **reflecting problems in the identification, registration and reporting of cases in Eastern countries**. Furthermore, there are inequalities in **prevention and early diagnosis**, with 70 per cent of melanomas in Germany being detected under 1 millimetre but fewer than 25 per cent in Romania. Inequalities also exist in **access to treatment**, with Eastern Europe having obtained access to reimbursed immunotherapies in the past four to five years only.

With a view to addressing cancer inequalities, the European Commission has recently launched a *European Inequalities Registry* as part of Europe's Beating Cancer Plan. The Registry provides data on cancer prevention and care, and identifies trends, disparities and inequalities between EU Member States and regions, showing inequalities linked to age, gender, socioeconomic status and geographical location.

In conclusion panellists gave their wish-lists of policies and partnerships to tackle skin diseases in the months and years to come, including:

- Continued and more intensive interaction between different stakeholders: patients, professionals, industry and policymakers
- Higher aspirations for skin disease treatment outcomes, with multi-disciplinary guidelines, improved patient literacy and partnerships being central to achieving them
- Increased involvement of patients, their families and other interested stakeholders
- Enhanced knowledge about rare diseases and their treatment, through aggregation of country data and development of new drugs
- Involvement of nurses in skin disease management
- Collaboration between patients organisations
- Philosophical shift in viewing the skin not as a barrier that needs repair, but as the interface that enables the connection between the person and the familial, professional and social environment
- Utilisation by EADV of its unique position as a European organisation to shape policies and partnerships at EU level whilst connecting with the complex and diverse patchwork of national realities

SESSION TWO
Reducing the impact of skin diseases on patients and healthcare systems

Measuring the impact of skin diseases on patients

Jennifer Austin
CEO, International Alliance of Dermatology Patient Organisations

Jennifer Austin presented the *GRIDD (Global Research on the Impact of Dermatological Diseases)* project, which is being undertaken by GlobalSkin in collaboration with its patient organisations around the world.

The project aims to empower patient organisations with **verifiable data** that they can use in their advocacy efforts in order to elevate the understanding and prioritization of skin diseases and to call for better access to care and treatment. 2100 patients from around the world have been involved in the development of the measure and were asked to define the questions that should be asked of them in order for them to be fully able to describe their experiences of living with their disease. The outcome of the project will be a **new measure of dermatological disease impact** - *Patient-Reported Impact of Dermatological Diseases (PRIDD)* - from the patients perspective, and will be a much more sensitive measure than the DLQI. Austin explained that it will transform the understanding of dermatology, so that the profound psychosocial impact of these diseases on patients is appreciated.

Earlier this year, GlobalSkin founded the *Global Dermatology Coalition* together with the International League of Dermatological Societies (ILDS), with the aim of working towards a WHO resolution on skin diseases in order to **elevate their policy prioritization in healthcare systems**, and Austin explained that the GRIDD data will feed directly into this work.

Panel discussion

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Global Albinism Alliance

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Matthias Augustin
Institute for Health Services Research in Dermatology and Nursing (IVDP), University Medical Center Hamburg-Eppendorf

Guy Fones
Head, Global Coordination Mechanism on NCDs, World Health Organisation

Measuring dermatological disease burden to inform decision- and policy-making

Austin reiterated the lack of data on dermatological conditions, and that furthermore, the data that is currently used to calculate Disability Adjusted Life Years (DALYs) is **not patient-centric**. None of the current measures of dermatological disease - including the DLQI - **meet best practice criteria**, and she called on the dermatology community to advocate for the use of **patient-led measures** (such as PRIDD).

Marie-Aleth Richard explained that current tools, measures and scales in dermatology were created for use in **clinical trials**, (i.e. to compare treatments), but measures of disease burden are urgently needed.

Fones explained that the main function of the World Health Organisation (WHO) is the setting of **norms and standards**, created from evidence-based information and data collection, and a major pillar of its work is in **strengthening healthcare delivery systems**.

Data collection and measurement is a pillar of strong, resilient healthcare systems, and monitoring, evaluation, surveillance, appropriate data collection and data dissemination are key components of health systems strengthening.

Fones said that data collection and measurement is important for use in advocacy, but it can also feed into **equitable and inclusive policy planning, standard setting and priority setting**.

The WHO is currently discussing how to integrate disease portfolios such as dermatological diseases, (which has been underserved in the health delivery system), into people-centred primary healthcare frameworks. Clear data is needed to support policy planning, standard setting and priority setting for health systems strengthening under the framework of universal health coverage (UHC), and for ultimately integrating dermatological diseases into UHC, benefit packages and financing mechanisms. Fones stressed that **data has to be collected, categorized and disaggregated for very specific opportunities and channels** including advocacy, policy design and

standard setting.

Fones also underscored the importance of **health literacy** and the **meaningful engagement of lived experience** for adequate disease measurement. Health literacy has been defined as a critical determinant of health and extends beyond individual patients to the level of communities and policymakers, so -called *health literacy responsive systems*. Fones added that it is important to enhance the health literacy of all these stakeholders, and to access underserved, less health literate populations. Finally, he cautioned against the use of the term 'patient engagement', instead preferring *lived experience of health conditions* which paves the way for a **broader understanding** of how people living with health conditions are navigating not only health systems but their lives, their families, relationships etc. and can help unpack **stigma, discrimination** etc.

The **role of patient organisations in data collection** was discussed, with Gliksohn confirming that patients organisations play an important role in **connecting with their communities to access data**. However, he cautioned that data collection requires **resources**, as well as specific expertise and skills. Not all patient organisations have access to such resources and this is particularly true of the rare disease community.

The issue of disability was discussed, with Gliksohn explaining that in France, criteria used to assess disability are outdated, having been developed after World War 1, when soldiers came back from the war with leg amputations, or being deaf or blind. Gliksohn called for the **updating of disability criteria** and **education of people in charge of assessing disability**, since they are not necessarily aware of the impact of skin disease on individuals, and the extent to which skin diseases can lead to disabilities.

Tackling stigmatization in skin diseases

Lack of knowledge and understanding about skin diseases amongst the general population may lead to **negative behaviours towards sufferers**, adding to the psychosocial burden of the disease. The *UN's Sustainable Development Goal 3.4* aims to reduce premature mortality from NCDs and to promote mental health and well-being, while the *WHO's 2014 Resolution on Psoriasis* underscores Member States' commitment to increase their efforts to fight stigma and unnecessary exclusion of people living with psoriasis.

Asked how far Member States have come in **tackling stigmatization** in skin diseases such as psoriasis, Fones responded that due to the **absence of a framework for accountability** against the work on stigmatization in psoriasis, they have likely **progressed much less than expected**. However, there is great potential in making progress on this issue through the **meaningful engagement of people living with such conditions**. He explained that when we unpackage patients' lived experiences, we start understanding the trigger points, and where the gaps are in supporting more equitable approaches and policies. When lived experiences are integrated in the co-design of policies, we may be able to address stigma and discrimination. Fones cited examples across other diseases where **human rights** approaches were used, such as the highly successful advocacy of the HIV/AIDS community who were able to shape policies to address discrimination and stigma and to tackle the multifaceted elements that impede equitable access, equitable care and well-being.

Gliksohn concurred with the importance of incorporating the human rights aspect into skin disease advocacy. Behind each patient is a person, who lives to be happy and to enjoy his or her human rights. The creation of a **coalition of stakeholders** would be an important step to create strong propulsion on this issue.

Elevating the prioritization of dermatological diseases

Austin referred to the formation of the *Global Dermatology Coalition*, an informal coalition of 21 organisations and companies active in the field of dermatology. No single stakeholder can solve the challenges we are facing alone, but when **patients, dermatologists and industry work together** on a common platform, priorities can be identified and a path forward charted. The Global Dermatology Coalition aims to elevate the prioritization of dermatological diseases, and Austin invited participants to visit the GlobalSkin website for further information.

Gliksohn explained that patients need support in the form of **education**, in order to manage their disease and to be able to advocate for themselves. In France, therapeutic patient education programmes are in development, where patients are educated about their disease and how to manage it on a daily basis. Furthermore, he added that having a physical disease very often affects **mental health**, so if mental health is not addressed, patients will most likely not be able to advocate for themselves.

A final word from the World Health Organisation

Fones provided information on two products that are in development by the WHO. First, **a guide for health literacy development for NCDs** is being produced, which includes the concept of health literacy responsive systems and how health systems can respond to different levels of health literacy. Second, a project will be launched early next year to operationalize the **meaningful engagement of people living with NCDs** and mental health conditions. This aims to support Member States with frameworks, best practices etc.

Fones concluded by recommending that we **expand our thinking** about disease measurement and develop a case for **investing** in the prioritization of skin diseases. He suggested reflecting on what skin diseases mean for finance ministries, health sectors, educational sectors and recommended developing **investment cases providing arguments for cross-sectoral attention**.

ABOUT EADV

Founded in 1987, the European Academy of Dermatology and Venereology is a global community with the unifying goal of advancing excellence in patient care, promoting knowledge and expertise among healthcare professionals, as well as advocating on behalf of the specialty and patients. It is a non-profit organisation with over 7000 members across more than 100 countries in the world, providing a valuable service for every type of dermato-venereologist professional. Learn more on **eadv.org**

For more information about EADV's advocacy and public affairs activities, please contact **publicaffairs@eadv.org**