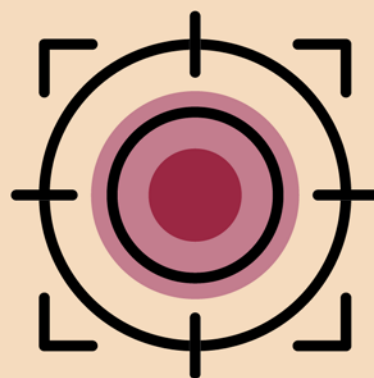




EUROPEAN
ACADEMY OF
DERMATOLOGY &
VENEREOLOGY

CALL TO ACTION ON
**CHRONIC
INFLAMMATORY
SKIN DISEASE**



This Call to Action has been endorsed by:

European & International Organisations



GLOBALSKIN.ORG
International Alliance of
Dermatology Patient
Organizations



International League
of Dermatological Societies



National Societies

Austrian Society of Dermatology and Venereology
Croatian Dermatovenereological Society of the Croatian Medical association
The Danish Dermatological Society
Estonian Society for Dermatovenereologists
Finnish Dermatological Society
French Society of Dermatology - Société Française de Dermatologie
Professional Association of German Dermatologists
Hellenic Society of Dermatology and Venereology
Italian Society of Medical, Surgical and Cosmetic Dermatology and of Sexually Transmitted Diseases
Lithuanian Association of Dermatovenereologists
Malta Eczema Society
Dutch Society of Dermatology and Venereology
Portuguese Society of Dermatology and Venereology
Slovak Dermatovenereological Society
Turkish Society of Dermatology
Ukrainian Academy of Dermatovenereology
British Association of Dermatologists

Foreword

Policymakers and stakeholders at EU and national levels have a powerful role to play in the improvement of health of those with chronic inflammatory skin disease across the European Union. The EADV and co-signatories call on the EU, Member States and stakeholder organisations to commit to driving forward positive change in the field of chronic inflammatory diseases across the following priority areas:



CALL 1: IMPROVING PUBLIC AWARENESS
AND REDUCING THE STIGMA OF SKIN DISEASE



CALL 2: TIMELY AND EQUITABLE ACCESS
TO HIGH QUALITY TREATMENT AND CARE



CALL 3: SUPPORTING THE DEVELOPMENT
OF NEW THERAPIES AND TECHNOLOGIES



CALL 4: ADDRESSING THE ECONOMIC
IMPACT ON THE INDIVIDUAL AND ON SOCIETY



CALL 5: CREATING AN ECOLOGICALLY
SUSTAINABLE FUTURE FOR DERMATOLOGY

List of abbreviations:

EU, European Union
HS, Hidradenitis Suppurativa
UK, United Kingdom
EADV, European Academy of Dermatology and Venereology
EMA, European Medicines Agency
JLA, James Lind Alliance
PSPs, Priority-Setting Partnerships
ERN, European Reference Network
BSDS, British Society of Dermatological Surgery
NHS, National Health system.
GIRFT, Getting It Right First Time

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Introduction

Skin diseases are common, and affect people at all life stages, from the neonatal period to old age – nearly one in two Europeans report having suffered from at least one dermatological condition in the last 12 months. Extrapolated to the European population, this means around 185 million people are affected.¹ The visible nature of many skin diseases may lead to stigmatisation, social isolation and victimisation of patients.

The full spectrum of skin diseases includes allergies, autoinflammatory diseases, autoimmune diseases, genetic diseases, vascular diseases, cancer, inflammatory diseases and infectious (viral, bacterial and fungal) diseases. Examples of inflammatory skin diseases are provided in this document, but are not exhaustive; there are more than 1,500 distinct skin conditions described.²

Chronic inflammatory skin disease such as atopic dermatitis, psoriasis, acne, rosacea and hidradenitis suppurativa are non-contagious, relapsing diseases, which are very common in European countries. They can affect people of any age. The common features of these conditions are dysregulation of the normal skin functions, resulting in visible skin changes, such as redness, scaling, crusting, and associated symptoms like itch, pain and sleep disturbance. These changes may have far-reaching effects on the patients' self-image, their emotional and social interactions, and the way that others in society respond to them. Economic productivity may also be affected. It may even lead to systemic inflammation and be associated to co-morbidities including but not limited to depression, cardiovascular disease, bowel disease and arthritis. Long-term treatment of chronic skin disease with agents such as systemic immunomodulatory drugs and corticosteroids may lead to their own complications such as cataract, osteoporosis and infection.

Less common chronic inflammatory skin diseases include:

- blistering disorders such as bullous pemphigoid and pemphigus vulgaris
- ulcerative conditions such as pyoderma gangrenosum
- intensely itchy conditions such as lichen planus
- pigmentary disturbance such as vitiligo
- hair loss conditions such as alopecia areata, lichen planopilaris and folliculitis decalvans

These conditions not only cause disruption to skin function, but also visible differences in the appearance of the skin, and symptoms disruptive to daily life. Due to their singularity, their diagnosis and treatment require access to expert dermatological teams. Research in the area of rare diseases is hampered by small numbers of cases of each condition, and challenges obtaining research funding for diseases affecting small numbers of people.

Chronic inflammatory skin disease causes a heavy burden of physical, social, emotional and economic impact for the individual, and for society as a whole. In spite of this, a tendency to dismiss dermatological disease as “just a rash” persists. An attitude that a dermatological disease is simply a “cosmetic” problem, rather than a systemic condition with far-reaching effects beyond the skin also forms part of societal misconception.

The EADV Burden of Skin Disease Survey was initiated in 2020 as a multinational, cross-sectional study aiming to define in the European population the prevalence of skin diseases, as well as factors pertaining to patient care, stigmatization, quality of life and satisfaction of the care that patients receive from dermatologists. The study demonstrated that of the 50% of Europeans who suffer from a dermatological disease each year, 70% described those diseases as severely affecting their quality of life. The survey also revealed disparities in access to expertise and to treatment across Europe. It was clear from the results that misconceptions about the nature of skin and venereal disease are prevalent in society.

Achieving high quality skin care for all patients with chronic inflammatory skin disease in Europe requires a coordinated approach. To guide future policy direction, we make 5 calls to action to tackle chronic inflammatory skin disease in Europe.



CALL 1: IMPROVING PUBLIC AWARENESS AND REDUCING THE STIGMA OF SKIN DISEASE

In addition to far-reaching effects on physical health, chronic inflammatory skin disease has a major impact on the mental health and quality of life of patients. Limitations on social, emotional, educational attainment, professional development and economic productivity of patients result from feelings of shame and embarrassment about their disease. Failure to thrive in these domains leads to significant levels of anxiety, depression and even suicidality.

Misconceptions about the causes of skin disease persist – for example, that they are infectious, contagious or related to inadequate hygiene. These beliefs create an environment where stigmatisation of those with skin disease can flourish.³ Poor health literacy in the field of chronic inflammatory skin disease leads to stigmatization, with some patients experiencing exclusion and discrimination in society.

Around 15-20% of patients with skin disease report feeling rejected by others due to their skin disease and this burden is particularly high amongst patients with psoriasis, hidradenitis suppurativa and vitiligo. Individuals with impaired physical and mental wellbeing due to a chronic skin disease tend to experience a higher level of perceived stigmatization.⁴ In turn, stigmatization can be a stressor that contributes to worsening of the skin disease itself.⁵

The 2014 World Health Assembly Resolution on Psoriasis encouraged Member States to engage in actions to reduce the stigmatization and discrimination of patients with psoriasis. However, only very few interventions to tackle stigmatization in skin disease have been implemented to date.

Good Practice Case Studies:

“In my Skin” - a German programme on ‘Destigmatization’ for patients with visible chronic skin diseases⁶

In response to the WHO’s call for action against stigmatization, the German Federal Ministry of Health commissioned a programme to evaluate if stigmatization can be prevented and pushed back.

The “In my Skin” programme engaged dermatologists, researchers, patients and policymakers, covering all visible chronic skin conditions.⁶ The study worked with these key stakeholders to determine how the development of stigma against those with skin disease can be combatted. Key findings were that targeted knowledge transfer, awareness-raising, education and building empathy can all help to halt the development of stigma.

Amongst researchers and doctors, this process should begin during undergraduate studies, and be continued during vocational training. Early introduction to the specific impacts of skin disease on patients is important for future doctors, nurses, allied health professionals and social workers. Engagement of those involved in early childhood education is critical in building better societal understanding of skin disease.

The “In my Skin” project aims to disseminate the findings of this research, and to put them in to practice – with and for those affected by skin disease.

Good Practice Case Studies:

Norwegian Hidradenitis Suppurativa Support Group: "HS Week"

This annual event is organised each year for one week at beginning of June to heighten awareness of HS.⁷ It is coordinated by the HS national patient organisation in Norway, and is a multi-stakeholder event, involving dermatologists, dermatology nurses, and allied health professionals, but also politicians and policy makers. It provides a platform for HS patients to tell powerful stories of their lived experience of the disease. Through this initiative, a large educational network has been established amongst general practitioners and family doctors in Norway, allowing earlier detection and better, faster treatment of HS.

Recommendations

European Commission

- Deliver actions to improve health literacy in skin disease through the EU's 'Healthier Together' non-communicable disease initiative.
- Earmark funding for studies to better understand the consequences of skin disease stigmatization, in particular on children and adolescents and its long-term effect as they become adults.
- Direct funding to research which aims to develop evidence-based interventions to reduce stigmatization.
- Ensure that research funding directed at reducing stigmatization of those with skin disease explores culture- and region-specific attitudes, by adopting a cross-border approach to such studies.
- Prioritise identification of groups particularly vulnerable to stigmatization, such as young men, those with long-standing untreated disease, and the overweight. Develop targeted strategies to meet the needs of these groups.
- Allocate funding through the EU4Health and other relevant funding programmes to support awareness campaigns aiming to destigmatize skin diseases, and to projects which aim to improve health literacy in skin disease.

Member States

- Expand and build on existing public awareness campaigns designed to educate populations accurately about the cause and the impact of chronic inflammatory skin disease and to address stigmatization (e.g. World Atopic Eczema Day, co-organized by the International Alliance of Dermatology Patient Organizations (GlobalSkin) and European Federation of Allergy and Airways Diseases Patients' Association (EFA)).
- Develop policies and legislation to protect people with chronic inflammatory skin disease from discrimination in the workplace and in educational institutions.
- Ensure that health literacy resources and campaigns are representative of all those with skin disease, including skin of colour and from different socioeconomic backgrounds.
- Allocate funds to initiatives that educate school-age children on common inflammatory skin diseases such as eczema and acne – e.g. educational resources which teach primary/elementary grade children about symptoms, treatments, and the fact that these conditions are not contagious or infectious.

Civil society organisations

- Advocate for policies and legislation to protect the rights of patients living with a chronic inflammatory skin disease.
- Work with and support patient organisations in their advocacy for skin health and quality of life.
- Promote inclusiveness of patients with dermatological diseases from all backgrounds into society and healthcare.
- Scientific societies should establish partnerships, and support evidence based advocacy of patient organisations.
- Devote resources to innovative projects involving patients to raise public awareness – e.g. humanities, music, art.



CALL 2: TIMELY AND EQUITABLE ACCESS TO HIGH QUALITY TREATMENT AND CARE

Certain skin diseases are associated with significant co-morbidities. Effects on physical health extend beyond the skin: liver, cardiovascular, joint and metabolic diseases such as diabetes and obesity are strongly associated with chronic inflammatory skin disease.⁸⁻¹²

Impressive advances in dermatology have been made in recent decades, including biologics and small molecules for psoriasis, atopic dermatitis, vitiligo, alopecia areata, hidradenitis suppurativa, prurigo nodularis, and the use of immunotherapy for the management of skin cancer.

These highly effective treatments can alter the whole disease course and the accompanying comorbidities for the better if introduced in a timely way. However, delays in accessing treatment are commonplace, and in some countries and regions, these therapies are not yet approved or reimbursed by healthcare systems creating inequalities across Europe.

Delays in accessing therapy can have serious implications for the physical and systemic health of patients with skin disease, increasing the risk of developing associated comorbidities such as cardiovascular disease and arthritis.^{13,14}

Often, complex and lengthy pathways must be navigated by patients in order to access appropriate care, with large inconsistencies among European countries. Within countries, geographic distribution of healthcare providers may contribute to difficulties accessing care for those in rural areas.

Spotlight on delayed diagnosis in Hidradenitis Suppurativa (HS)

HS is a chronic disease of the skin characterized by the formation of very painful odorous purulent abscesses and fistulae (skin tunnels), mainly in the major skin folds such as the armpits and groin. Patients feel embarrassed and may avoid seeking help, together with the failure of general physicians to recognize this disease, it means that patients with HS see an average of five or more physicians over more than 10 years before being diagnosed.^{15,16}

The impacts of skin disease on mental health are common, with anxiety and depression frequently reported. A survey in the UK found that 98% of patients with psoriasis described a negative impact of the disease on their psychological well-being, of whom 5% had suicidal thoughts linked to their condition. However only 19% of patients reporting a psychological impact of their skin disease had received psychological support.^{17,18}

Early expert intervention can transform patients' experience of chronic inflammatory skin disease. This was emphasized in the Getting It Right First Time (GIRFT) report, commissioned by the Director of National Health Service (NHS) Clinical Improvement in the UK.¹⁹

The report underlined the benefits in terms of physical and mental health to dermatology patients of being seen in the right place, at the right time, by the right healthcare provider, at the earliest possible opportunity. This approach is well-illustrated in the case study 'The Manchester Psoriasis Rapid Access Clinic'.²⁰

Good Practice Case Study:

The Manchester Psoriasis Rapid Access Clinic

The Manchester Psoriasis Rapid Access Clinic was established in 2019 as an exemplar in the effective early management of a chronic inflammatory skin disease. Recognising the multi-faceted impact of this complex immune disease on skin, cardiovascular, liver, joint and psychological health, the clinic gathered a multidisciplinary team to assess patients in a holistic way. At the initial assessment, in addition to evaluation of the skin, patients were screened for diabetes and obesity, and other cardiovascular risk factors such as cholesterol, high blood pressure and smoking. The patient's psychological health was also evaluated using standardized tools for detecting anxiety and depression. In the first 6 months of the clinic, more than a quarter of patients met the criteria for depression; more than a third the criteria for anxiety. More than a third had untreated hypertension, and 50% had high cholesterol. Appropriate, effective treatments for skin disease and any accompanying comorbidities can be implemented early in the disease course, thus minimizing the physical, emotional and economic aspects of disease.

Recommendations

European Commission

- Ensure that the EU's Pharmaceutical Strategy and revised pharmaceutical legislation address the barrier of cost to the delivery of effective treatments across Member States and foster equitable access to advanced technology and medicinal products.
- Provide incentives to industry to ensure continuing supplies of useful treatments with lower profit margins. If a particular product is to be removed, a suitable alternative must be arranged. Supplies of off-patent medications critical for maintaining control of skin disease should be assured.
- Teledermatology offers an innovative solution to some of the geographic challenges of accessing healthcare. Support projects, via the EU4Health, Horizon Europe and other funding programmes, to develop effective teledermatology solutions to facilitate early diagnosis, support self-management, and to promote inclusivity of access to care. Ensure parallel promotion of digital literacy.
- Through the European Artificial Intelligence Strategy, support the development and uptake of AI in the area of skin health, protecting citizens from the introduction of technologies and interventions which are without a firm evidence base, for example devices that have not been adequately tested.
- Ensure that the upcoming EU Mental Health Strategy recognizes skin disease and its stigmatization as a risk factor for reduced mental health, and includes actions to mitigate and respond to mental health challenges in the field of skin disease.
- High quality dermatology care can be provided by a multidisciplinary team. The EU should seek to support the training and education of different HCP groups (doctors in primary care, nurses, pharmacists, physician associates) to provide dermatology in the community, in primary care and in secondary care, improving access to expertise.

Member States

- Invest in programmes seeking to improve early detection of chronic inflammatory skin disease such as eczema, psoriasis and HS.
- Implement recommendations from European Guidelines such as those developed by the EADV, for example EADV Guidelines for the management of Psoriasis and Eczema.

- Ensure that access to paediatric dermatology is adequate to minimize the impact of inflammatory skin diseases prevalent in childhood such as eczema on physiological, emotional, societal and intellectual development, particularly in Early Years.
- Standardise assessment of quality of life (QoL) impact by using validated, objective QoL tools designed to measure this parameter. Use results to standardise access to mental health support as part of holistic care of patients living with skin disease.
- Support the extension of roles of different health care provider's groups providing dermatology in the community, in primary care and in secondary care, to reflect the increasing sophistication and complexity of treatment options.^{21,22}
- Use data such as that collected by disease registries to identify target populations that struggle to access dermatological care, such as those in remote or rural areas, those experiencing financial hardship, those living with disability, and the elderly.
- Set standards for geographic location of dermatology services, ensuring that care is distributed equitably: those living in rural and remote areas should not be disadvantaged in accessing care. Equally, essential dermatological care should be available to the financially disadvantaged without barrier of cost in Member States.
- Where access to care may be challenging, for logistical reasons, advocate for digital solutions to overcome this.
- Develop policies and legislation to foster the secure use of teledermatology.
- Integrate the recording of quality of life data as a routine part of the care of patients with chronic inflammatory skin disease, developing digital solutions for delivery.
- Direct funding to programmes that specifically target education of patients about self-care, and the importance of seeking advice from health care providers about dermatological matters in a timely fashion
- Education and training of more dermatologists in countries where there is a shortage of experts.
- Ensure that there are at least regional comprehensive multidisciplinary psychodermatology units established throughout the EU Member States.

Civil society organisations

- Foster patient support groups with predicated funding.
- Develop patient decision aids that meet international standards.
- Optimise integration of patients' involvement in guideline formulation, participation in clinical trials, and medicines approval.
- Support the development of patients apps assessing co-morbidities, drug intake, symptoms and disease severity – important tools for improving self-management and improving digital literacy.



CALL 3: SUPPORTING THE DEVELOPMENT OF NEW THERAPIES AND TECHNOLOGIES

Dermatology has been pioneering amongst medical specialties in the development of new targeted immunological therapies for the last 20 years. These sophisticated treatments have the power to change lives and to alleviate heavy burdens of inflammatory disease, with many fewer side effects than older therapies. Many novel treatment developments have occurred in dermatology, such as the advent of biological therapies for psoriasis and eczema, and in specialties such as oncology, gastroenterology, and rheumatology.

However, important research gaps continue to exist in many neglected disease areas, such as in HS and systemic lupus erythematosus, creating an imperative for a research-active environment. Hence, Europe has the opportunity to foster the development of these technologies and therapies within European countries, retaining its economic value of such discoveries. Therefore, it is important to foster and engage scientific and medical talent, which too often migrates to outside of Europe, such as to the US.

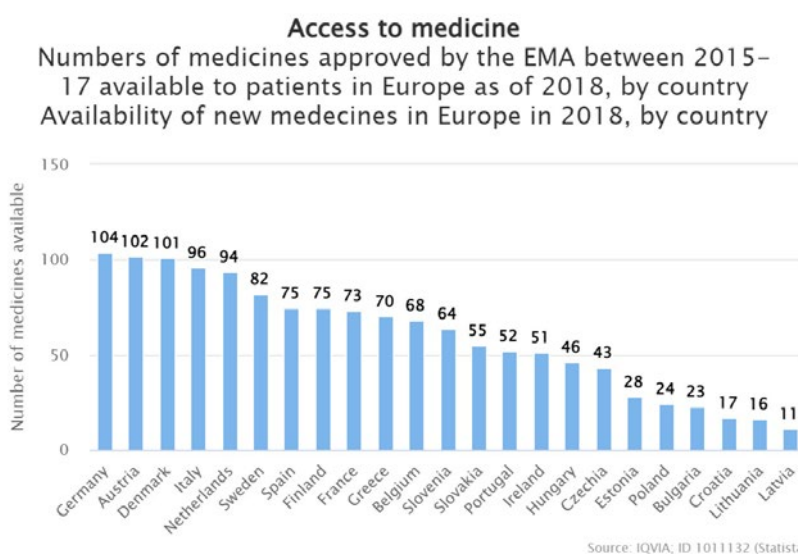
Data on the burden of skin disease in Europe is currently insufficient. Disease registries would help to fill this information void. The sharing of knowledge and generation of large datasets is the most powerful tool we have to detect adverse events, side effects and to recognize patterns of disease. Registries would also allow identification of future research priorities.

Personalised medicine has the potential to create seismic shift in the therapeutic landscape of dermatology. Personalised medicine describes the use of genetic signatures, disease or patient characteristics to predict which treatment will best work for an individual patient. Promoting entry to disease registries, and establishing biobanks are important components of advancing the concept of personalized medicine.

Involvement of patients in determining the research agenda is essential. By engaging patients across Europe in priority-setting partnerships, outcomes of importance to patients can be focused upon and research goals set accordingly.

Spotlight on inequalities in access to medicines

Considerable inequalities exist between EU Member states in terms of access to approved medicines. The graph on the right demonstrates the number of medicines approved by the EMA between 2015 and 2017, available by 2018 to patients, displayed according to country. It is clear that even for approved medications, inequalities exist between EU Member States.



The European Commission has released the discussion paper: “Scoping study on evidence to tackle high-burden under-researched medical conditions” identifying groups of disorders of high-burden under-researched medical conditions.²³

Four out of the 12 (33%) groups identified are dermatovenereology conditions:

- 1) Skin and subcutaneous diseases: atopic dermatitis, HS, Genital Lichen Sclerosus, Lichen Planus
- 2) Conditions related to sexual health
- 3) Immune related diseases Allergy (food allergy), Autoimmune diseases, Mast cell activation syndrome and
- 4) Other: Chronic Lyme disease, Hypermobility Ehlers Danlos Syndrome

The discussion paper considers that these diseases currently receive insufficient research funding, considering their significant burden on patients and society.

Good Practice Case Study:

The James Lind Alliance (JLA)²⁴

The JLA is a non-profit initiative that brings patients, carers and clinicians together in Priority-Setting Partnerships (PSPs). The PSP identify and prioritise crucial unanswered questions or evidence uncertainties, so that health research funders are aware of the issues that matter most to patients. The JLA has led PSP in some of the major chronic inflammatory skin diseases such as eczema, acne, psoriasis, vitiligo and HS. The result of these PSPs has helped to set a roadmap for future research in these areas. As an example, the PSP for psoriasis identified two top research priorities: “Do lifestyle factors such as diet, dietary supplements, alcohol, smoking, weight loss and exercise play a role in treating psoriasis?”, and secondly “Does treating psoriasis early (or proactively) reduce the severity of disease, making it more likely to go in to remission, or stop other health conditions developing?”. Having evidence-based scientific replies to both questions could drastically impact the way that psoriatic patients are treated, leading to improved health, quality of life and lower socioeconomic medical costs.

Recommendations

European Commission

- Allocate funding from the Horizon Europe programme to support research into high-burden, under-researched chronic inflammatory skin diseases (as mentioned above from the European Commission’s scoping study), as well as to qualitative research on the impact of living with skin diseases in different life stages, from infancy to old age.
- Augment funding for the European Reference Networks (ERN) such as ERN-Skin to allow subgroups to extend existing work, to share learning between members, and to expand participation in dermatological research for rare chronic inflammatory skin diseases.
- Encourage a diverse population in geographic and demographic terms to participate in research.
- Set policy positions which facilitate movement of data, biological samples and reciprocal acknowledgement of ethical approval across Member States.
- Through the EU Pharmaceutical Strategy, incentivize responsible research and drug development by the pharmaceutical industry to meet needs as determined by patients and clinicians.
- Specifically promote drug and treatment development in rare or orphan diseases which may otherwise be neglected.

- For Advanced Therapy Medicinal Products, protect academic innovation, research and development by maintaining a separate regulatory pathway from that imposed on industry.
- Support the formation of European Disease Registries for common and rare skin disease.

Member States

- Support innovative partnerships (e.g. public-private partnerships) for the development of therapies for rare chronic inflammatory skin disease.
- Support the establishment of national disease registries for dermatological diseases
- Expand the research funding opportunities for high-burden, under-researched dermato-venereological conditions.
- Foster career progression of skin scientists.
- Incentivize multi-national or multidisciplinary research collaborations.

Civil society organisations

- Provide input from the dermatology scientific, clinical and patient community on gaps in chronic inflammatory skin disease research in order to support the European Commission in designing Horizon Europe work programmes.
- Facilitate the participation of all stakeholders in setting research priorities, for example through provision of funding for participation in priority-setting partnerships and initiatives.



CALL 4: ADDRESSING THE ECONOMIC IMPACT ON THE INDIVIDUAL AND ON SOCIETY

Disability conferred by living with skin disease may be physical, social or emotional, and both can impact on the ability of a patient to be and to remain economically active.²⁵⁻²⁷ Many factors can contribute to instability of employment, or participation in education:

- stigmatization of the individual with a visible difference
- time off required for attendance at hospital appointments
- intercurrent illness contracted due to the immunosuppressant effects of treatment
- physical symptoms such as pain, itch or fatigue

Patients with chronic skin diseases in particular may be often absent from work because of physical disability (absenteeism), or even if they are able to work, their productivity may be decreased (presenteeism). These factors, coupled with lower levels of educational attainment due to disruption of education and sleep disturbance, may have a life-long negative impact on career progression.

In the Burden of Skin Disease Survey, 83% of respondents considered their skin disease to be an embarrassment at work. 45% reported experiencing at least one of the following as a consequence of their skin disease:

- Need to adapt working hours
- Need to reorientate professional activity
- Failure to secure professional advancement
- Failure to secure a desired job/position

Skin disease may impede the individual from engaging in non-paid caring responsibilities such as for children or an elderly parent.

Untreated chronic inflammatory skin diseases are more likely to be associated with comorbid conditions such as high blood pressure, diabetes and arthritis than those with effectively-treated skin disease. These comorbidities and their management have an additional health economic impact in those with chronic inflammatory skin disease.

Reimbursement of costs of essential skin care treatments such as emollients and sunscreens vary from country to country within the EU. In settings where state subsidy is not provided, the financial burden of treatment may be considerable, in some cases forming a barrier to effective management.^{28,29} Providing affordable basic treatments is an important responsibility of government, and of pharmaceutical regulators. EU level legislation and recommendations should be used to mandate this provision.

Spotlight on children with atopic dermatitis – the impact on the individual and the family

Children with poorly managed atopic dermatitis (AD) have demonstrably poorer educational outcomes than children without AD.³⁰ Disruption to sleep, persistent itch, stigmatization by fellow pupils may all contribute to reduced educational attainment^{31,32} Family life is frequently affected by caring for a child with atopic dermatitis, in social, economic and emotional terms.³³ Education has been used as a powerful tool to overcome these challenges. “Atopic Kindergartens”, “Atopic Schools”, and targeted education programmes have all been successfully employed in Europe to address these challenges.^{34,35} Such interventions have been demonstrated to reduce the incidence of flares of atopic dermatitis in children, to improve sleep scores, and to improve school attendance. Extending such programmes would offer a valuable opportunity to the European community to improve public knowledge about atopic dermatitis, and to reduce stigmatization of this devastating condition.

Recommendations

European Commission

- Use legislation and recommendations to ensure that access to basic and advanced treatments for skin disease is equitable and affordable across Europe.
- Through EU Health and Safety policies, encourage provision by employers of facilities which protect patients with skin disease in the workplace – e.g. access to appropriate personal protective equipment, provision of facilities for washing, application of topical treatments.
- Consider applying the concept of joint procurement for treatments for rare diseases, to allow more equitable access across the EU, particularly smaller EU states.

Member States

- Mandate reasonable modification of environments for patient with chronic inflammatory skin disease.
- Recognise the impact of occupational dermatoses (hand eczema in nurses, contact allergic dermatitis in hairdressers), and existing skin conditions exacerbated by work environment (atopic dermatitis patients working in dusty environments such as a factories).
- Support the fair implementation of existing employment law to allow patients with skin disease to remain economically active while attending to their treatment; for example, ensuring that reasonable adaptations to work can be made to facilitate ongoing employment.
- Ensure that employment rights and responsibilities recognize the full impact of skin disease on the individual.
- Ensure that cost is not an insurmountable barrier to access to basic skin treatments such as emollient and sunscreen, by designing reimbursement schemes or subsidizing prices of medically-required topical therapies.

Civil society organisations

- National Societies and patient organisations should design educational resources aimed at employers and educators to promote public health awareness of the ramifications of skin disease.
- National Societies and patient organisations should provide information and advice for patients with skin disease on their rights as employees, and the protection afforded to them by employment law.



CALL 5: CREATING AN ECOLOGICALLY SUSTAINABLE FUTURE FOR DERMATOLOGY

Health and social care contribute significantly to the overall carbon emissions in European countries.³⁶ Dermatology has a duty to provide a cleaner, greener future for the specialty.

Assessment of the impact of specific areas of dermatology has been made. Mohs micrographic surgery produces an average of 0.52kg of waste per procedure. In response to these findings, some dermatology organisations have produced guidelines on reducing the carbon footprint of surgery.^{37,38}

The dermatology community looks to the EU to make policy and legislative decisions which promote a greener, more sustainable future for skin care, as part of Europe's commitment to becoming the world's first climate-neutral continent by 2050.

The aspiration should be for excellent care of those with inflammatory skin disease to have the lightest carbon footprint possible. This is a far-reaching aspiration, and would incorporate many elements from the global to the local:

Industry

- Legislation to mandate greener manufacturing processes for the pharmaceutical industry
- Increased use of recycled and recyclable materials in packaging of dermatological products
- Green solutions for supply chains, favouring land-based transport over air freight

Hospitals and Clinics

- Energy-efficient buildings for care delivery
- Optimise use of teledermatology solutions to cut down on patient journeys
- Responsible waste management systems which minimize landfill

The European Commission's One Health approach recognizes the interdependence of human and environmental health, chiming with this need to establish a green, sustainable future for dermatology.³⁹ The impact of climate change on skin health is likely to be considerable. Increasing levels of ultraviolet irradiation in sunlight are likely to translate in the future to an increased burden of skin cancer.⁴⁰ Certain dermatoses, both common (such as some forms of eczema) and rare (such as lupus) may be exacerbated by sunlight, the levels of which are expected to increase.

Good Practice Case Study:

The Green Initiative: improving environmentally sustainable practice and optimizing waste management in Cardiff dermatology department

The UK's National Health system (NHS) contributes to one-fourth of the greenhouse gas emissions within the public sector in the UK.⁴¹ The campaign "For a Greener NHS" was initiated in January 2020 to strengthen the effort of the organisation in the last decade in achieving net-zero emissions by 2040.⁴²

The Cardiff dermatology department measured the environmental and economic costs of single-use versus reusable instruments, demonstrating carbon and cost savings in switching to reusable instruments. They also updated their recycling procedures by introducing recycling bins into procedure rooms and surveying staff about sustainable practice.⁴³

Other measures included:

- Review and introduce the BSDS Sustainability guidance (mentioned above in spotlight section)
- Online meetings, including for multi-disciplinary team meetings, regional and national professional meetings
- Teledermatology, such as triage photo referrals with advice for management in primary care, getting patients take own photos for day-2 patch testing reading and for surgical follow-up ('wound selfie')
- Instead of printing Patient Information Leaflets, use the embedded QR codes referring to the leaflets. Patients with smartphones can scan the codes using their phone camera or a QR code reader app and it will bring up the link on their device

Recommendations

European Commission

- Foster responsible, sustainable waste disposal in all health care settings across the EU.

Member States

- Direct funding to assist the integration of recycling streams into all hospital waste disposal⁴⁴
- Mandate lean supply chains.
- Control pharmaceutical packaging/packaging of treatments to incorporate recycled and recyclable materials whenever possible.
- Encourage carbon-light manufacturing processes for pharmaceutical companies.
- Fund awareness campaigns regarding the need for UV protection when outdoors.
- Encourage prescribing practices which minimize waste, and prevent "stock-piling" of medication which may date-expire before use.

Civil society organisations

- Design patient-directed education programmes which promote responsible, non-wasteful use of topical therapies.
- Encourage national patient support groups for skin disease to promote environmentally sound skin care, such as information regarding recycling packaging.

Conclusion

The burden of chronic inflammatory skin disease in Europe is considerable: alleviating the far-reaching impact of this requires a coordinated, multifaceted approach. This invitation to action has been formulated to address not only the physical and therapeutic needs of people with a diagnosis of a chronic inflammatory skin disease – we also call for the social, emotional and economic impact of these diseases on the individual, the family and the community to be taken into consideration. It is imperative that a holistic approach is taken if the challenge of chronic inflammatory skin is to be met successfully. If coordinated efforts are made at European, national and local level, we can ensure a bright, equitable and sustainable future for all those living with chronic inflammatory skin disease.

References

- Richard MA, Paul C, Nijsten T, et al. Prevalence of most common skin diseases in Europe: a population-based study. *J Eur Acad Dermatology Venereol* 2022; 36:1088–96.
- Principles of dermatological practice. Overview | DermNet [WWW Document]. URL <https://dermnetnz.org/cme/principles/an-overview-of-dermatology> [accessed on 7 September 2023].
- Van Beugen S, Schut C, Kupfer J, et al. Perceived Stigmatization among Dermatological Outpatients Compared with Controls: An Observational Multicentre Study in 17 European Countries. *Acta Derm Venereol* 2023; 103:adv6485.
- Dalgard FJ, Bewley A, Evers AW, et al. Stigmatisation and body image impairment in dermatological patients: protocol for an observational multicentre study in 16 European countries. *BMJ Open* 2018; 8:e024877.
- Koumaki D, Efthymiou O, Bozi E, Katoulis AC. Perspectives On Perceived Stigma And Self-Stigma In Patients With Hidradenitis Suppurativa. *Clin Cosmet Investig Dermatol* 2019; 12:785–90.
- Together against stigmatization | In my Skin [WWW Document]. URL <https://www.in-my-skin.info/> [accessed on 11 July 2023].
- Useful info | Live with HD [WWW Document]. URL <https://www.levmedhs.no/nyttig-informasjon/hs-awareness-week> [accessed on 7 September 2023].
- Kwa MC, Silverberg JI. Association Between Inflammatory Skin Disease and Cardiovascular and Cerebrovascular Co-Morbidities in US Adults: Analysis of Nationwide Inpatient Sample Data. *Am J Clin Dermatol* 2017; 18:813–23.
- Lee SW, Kim H, Byun Y, et al. Incidence of Cardiovascular Disease After Atopic Dermatitis Development: A Nationwide, Population-Based Study. *Allergy Asthma Immunol Res* 2023; 15:231–45.
- Ren Z, Narla S, Hsu DY, Silverberg JI. Association of serious infections with pemphigus and pemphigoid: analysis of the Nationwide Inpatient Sample. *J Eur Acad Dermatology Venereol* 2018; 32:1768–76.
- Shaheen MS, Silverberg JI. Association of inflammatory skin diseases with venous thromboembolism in US adults. *Arch Dermatol Res* 2021; 313:281–9.
- Narla S, Silverberg JI. Multimorbidity and mortality risk in hospitalized adults with chronic inflammatory skin disease in the United States. *Arch Dermatol Res* 2020; 312:507–12.
- Acosta Felquer ML, Logiudice L, Galimberti ML, et al. Treating the skin with biologics in patients with psoriasis decreases the incidence of psoriatic arthritis. *Ann Rheum Dis* 2022; 81:74–9.
- Gisondi P, Bellinato F, Targher G, et al. Biological disease-modifying antirheumatic drugs may mitigate the risk of psoriatic arthritis in patients with chronic plaque psoriasis. *Ann Rheum Dis* 2022; 81:68–73.
- Saunte DM, Boer J, Stratigos A, et al. Diagnostic delay in hidradenitis suppurativa is a global problem. *Br J Dermatol* 2015; 173:1546–9.
- Garg A, Neuren E, Cha D, et al. Evaluating patients' unmet needs in hidradenitis suppurativa: Results from the Global Survey Of Impact and Healthcare Needs (VOICE) Project. *J Am Acad Dermatol* 2020; 82:366–76.
- Sampogna F, Tabolli S, Abeni D. Living with psoriasis: prevalence of shame, anger, worry, and problems in daily activities and social life. *Acta Derm Venereol* 2012; 92:299–303.
- All-Party Parliamentary Group on Skin. Mental Health and Skin Disease [WWW Document]. All Party Parliam. Gr. Ski. Ment. Heal. Ski. Dis. 2020; :1–78.
- Dermatology - Getting It Right First Time - GIRFT [WWW Document]. URL https://gettingitrightfirsttime.co.uk/medical_specialties/dermatology/ [accessed on 7 September 2023].
- Reid C, Welsh C, Martin-Smith H, et al. A rapid access clinic for psoriasis: first experiences. *Br J Dermatol* 2022; 187:426–8.
- Courtenay M, Carey N. A review of the impact and effectiveness of nurse-led care in dermatology. *J Clin Nurs* 2007; 16:122–8.
- van Os-Medendorp H, Deprez E, Maes N, et al. The role of the nurse in the care and management of patients with atopic dermatitis. *BMC Nurs* 2020; 19. doi:10.1186/S12912-020-00494-Y.
- Scoping study on evidence to tackle high-burden under-researched medical conditions - discussion paper. | Nivel [WWW Document]. URL <https://www.nivel.nl/en/publicatie/scoping-study-evidence-tackle-high-burden-under-researched-medical-conditions-discussion> [accessed on 11 July 2023].
- James Lind Alliance. James Lind Alliance (JLA) [WWW Document]. 2023.
- Villacorta R, Teeple A, Lee S, et al. A multinational assessment of work-related productivity loss and indirect costs from a survey of patients with psoriasis. *Br J Dermatol* 2020; 183:548–58.
- Tzellos T, Yang H, Mu F, et al. Impact of hidradenitis suppurativa on work loss, indirect costs and income. *Br J Dermatol* 2019; 181:147–54.
- Jabłonowska O, Woźniacka A, Szkarłat S, Żebrowska A. Female genital lichen sclerosus is connected with a higher depression rate, decreased sexual quality of life and diminished work productivity. *PLoS One* 2023; 18. doi:10.1371/journal.pone.0284948.
- Zink A, Arents B, Fink-Wagner A, et al. Out-of-pocket Costs for Individuals with Atopic Eczema: A Cross-sectional Study in Nine European Countries. *Acta Derm Venereol* 2019; 99:263–7.

References

29. Towfighi P, Huffman SS, Bovill JD, et al. Financial toxicity of hidradenitis suppurativa: A single-center experience at an urban wound-care clinic. *J Dermatol* 2023. doi:10.1111/1346-8138.16868.
30. Schmidt SAJ, Mailhac A, Darvalics B, et al. Association Between Atopic Dermatitis and Educational Attainment in Denmark. *JAMA dermatology* 2021; 157:1–9.
31. Chamlin SL, Mattson CL, Frieden IJ, et al. The price of pruritus: Sleep disturbance and cosleeping in atopic dermatitis. *Arch Pediatr Adolesc Med* 2005; 159:745–50.
32. Lewis-Jones S. Quality of life and childhood atopic dermatitis: The misery of living with childhood eczema. *Int J Clin Pract* 2006; 60:984–92.
33. Yang EJ, Beck KM, Sekhon S, et al. The impact of pediatric atopic dermatitis on families: A review. *Pediatr Dermatol* 2019; 36:66–71.
34. Barbarot S, Bernier C, Deleuran M, et al. Therapeutic patient education in children with atopic dermatitis: position paper on objectives and recommendations. *Pediatr Dermatol* 2013; 30:199–206.
35. García Soto L, Martín Masot R, Espadafor López B, et al. Evaluation of atopy schools for parents. *Allergol Immunopathol Int J Clin Investig Allergol Clin Immunol* ISSN 0301-0546, ISSN-e 1578-1267, Vol 49, No 2, 2021, págs 1-5 2021; 49:1–5.
36. Allwright E, Abbott RA. Environmentally sustainable dermatology. *Clin Exp Dermatol* 2021; 46:807–13.
37. Chaplin CL, Wernham AGH, Veitch D. Environmental sustainability in dermatological surgery. *Br J Dermatol* 2021; 184:952–3.
38. Fatima A, Rachel AD, Aaron WD. BSDS Sustainability Guidelines [WWW Document]. 2022.URL https://bsds.org.uk/wp-content/uploads/2022/09/2022-BSDS_Sustainability_Guidance.pdf [accessed on 20 May 2023].
39. Overview [WWW Document]. URL https://health.ec.europa.eu/one-health/overview_en [accessed on 7 September 2023].
40. The Lancet Oncology. Climate change and skin cancer: urgent call for action. *Lancet Oncol* 2023; 24:823.
41. Breaking the fever: Sustainability and climate change in the NHS | RCP London [WWW Document]. URL <https://www.rcplondon.ac.uk/projects/outputs/breaking-fever-sustainability-and-climate-change-nhs> [accessed on 11 July 2023].
42. Net Zero Teesside | The UK's first decarbonised industrial cluster [WWW Document]. URL <https://www.netzeroteesside.co.uk/> [accessed on 11 July 2023].
43. O10: The Green Initiative: improving environmentally sustainable practice and optimizing waste management in a dermatology department. *Br J Dermatol* 2021; 185:12–3.
44. Shearman H, Yap SM, Zhao A, et al. A United Kingdom-wide study to describe resource consumption and waste management practices in skin surgery including Mohs micrographic surgery. *Clin Exp Dermatol* 2023. doi:10.1093/CED/LLAD184.