IFPA Forum 2022

A roadmap for patient associations to improve care for people with psoriatic disease

Speaking up for psoriatic disease in Europe

IFPA
FORUM
EUROPE 2022

Hoseah Waweru,
President of IFPA, introduces the IFPA 2022 Forum

Contents

Introduction

In September 2022, stakeholders gathered in Milan, Italy, for the first-ever IFPA Forum on psoriatic disease. The Forum brought together stakeholders from the psoriatic community to promote regional action. The focus was on Europe, but global representation gave the Forum an international perspective. Psoriatic associations, thought leaders, people living with psoriatic disease, civil society representatives, medical professionals and private sector representatives collaborated to find ways to overcome gaps, and discussed the need for new ways of working together.

The overriding message was that a **united effort is needed** to elevate psoriatic disease on national health agendas and realize a collective vision of life free from needless suffering and stigma for all people affected by psoriatic disease.

The Forum focused on the five themes for prioritizing actions, identified by IFPA members in Europe as the most urgent topics to address. This report summarizes key points from the discussions held at the Forum and presents a roadmap for action.

The first IFPA Forum has set the course, and it is now up to patient associations, other stakeholders involved in the cause and people living with psoriatic disease, in every country, to implement the roadmap. The roadmap should be adapted to the national context in order to achieve our ultimate vision for all people living with psoriatic disease to enjoy good health and well-being, free from stigma and preventable disability and comorbidities.

Paving the way to action

Access to care (early diagnosis and finance for care)

IFPA FORUM 2022 THEMES

Patient associations decided on the themes relevant to speaking up for psoriatic disease in Europe.

IFPA

Speaking up for psoriatic disease in Europe

JULY 2022

Start reading

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BRIEFING BOOK: Speaking up for psoriatic disease in Europe

A patient association editorial group supported the development of an evidence-based briefing book on psoriatic disease in Europe ahead of the Forum. The briefing book is published and used by advocates across Europe.

Speaking up

IFPA FORUM

5 September 2022
Milan, Italy
Unahotels Expo Fiera Milano

Draft agenda

IFPA FORUM 2022: 5 September

Guest speakers, patient associations and healthcare professionals came together at the IFPA Forum in Milan to discuss the themes and ways to improve care. The discussion at the IFPA Forum informed the development of the roadmap.

IFPA Forum 2022
A roadmap for patient associations to improve care for people with psoriatic disease

Speaking up for Psoriatic Disease in Europe

IFPA FORUM

IFPA FORUM 2022: A roadmap for patient associations to improve care for people with psoriatic disease

The patient association editorial board provided input for shaping the roadmap recommendations and actions. The roadmap is a guide for patient associations when formulating local, context-specific action plans.

Five key recommendations

Several key recommendations were taken from the IFPA Forum 2022 discussions that patient associations should consider when setting the direction and identifying actions to improve care for people living with psoriatic disease locally. IFPA recommends the following steps going forward.

Patient associations should advocate for a people-centred approach and empower people living with psoriatic disease to speak about their mental health.

WHY?

A better understanding of the relationship between mental health and psoriatic disease is urgently needed.

HOW?

Patient associations can support healthcare providers with their lived experience knowledge, in order for HCPs to take an effective and holistic approach to clinical appointments.

Patient associations should advocate to policymakers for a multidisciplinary approach and greater investment, to improve access to care and enable early diagnosis.

WHY?

Patient associations are uniquely placed to play an active role in providing an evidence base for the various treatments and to advocate for greater investment in NCDs.

HOW?

Patient associations should advocate for an integrated team approach, to consider all relevant treatment options and develop an individual treatment plan with the person living with psoriatic disease.

Patient associations can be the driving force in bridging communication gaps between patients, general practitioners and specialists.

WHY?

Communication gaps are a persistent problem, and associations should empower patients to play an educating role with regard to their disease.

HOW?

Patient associations can support patients and healthcare professionals with communication tools and share ideas for better practices.

People living with psoriatic disease should be more involved in their care decision-making process.

WHY?

Patient involvement leads to higher levels of satisfaction with care, increased knowledge about treatments, more realistic expectations of treatment and greater adherence.

HOW?

Patient associations should advocate for greater involvement by working with NCD organizations to align on pathways for greater involvement and influence.

Telehealth should be considered in order to improve gaps in access to care, and a safeguarding framework would support this.

WHY?

Routine appointments or sharing results in a digital meeting could reduce the strain on clinic appointment slots, improve efficiency and close gaps in access to care.

HOW?

Patient associations should advocate for greater use of telemedicine but also voice patient concerns regarding privacy, security and digital accessibility.

Welcome note and event moderators

Hosea Waweru
President of IFPA

Frida Dunger Johnsson
Executive Director, IFPA

Craig Ludwig
Managing Director, Last Mile

Forum speakers

Joel Nelson, United Kingdom
Person living with psoriatic disease and IFPA Ambassador

Yochai Schonmann, MD, MSc, Israel
Lead, Health care Quality Indicators Program for Clalit Health Services Hospital

Ingvar Ingvarsson, Iceland
Member of Spoex/The Icelandic Psoriasis and Eczema Foundation Reykjavik, Iceland, Vice president of IFPA

Marianne Takki
Team Leader, Health promotion, disease prevention, financial instruments unit, European Commission

Prof. Dr. Matthias Augustin, Germany
Director of the Institute of Health Care Research in Dermatology and Nursing, University Medical Center Hamburg-Eppendorf

Arnon Cohen, MD, MPH, PhD, Israel
Director, Department of Quality Measurement, Clalit Health Services Hospital, Ben-Gurion University of the Negev

Alison Cox, United Kingdom
Policy and Advocacy Director, NCD Alliance

Valeria Corazzo, Italy
President of APIAFCO

Forum themes discussed

Five forum themes guided the discussion on the day. In the months prior to the event, IFPA members in Europe selected these themes as important topics they were keen to prioritize and address within the region. The next section highlights the key points from the fruitful session discussions.

~ 6.4m people

are living with psoriasis in Europe[1]

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1. Global Psoriasis Atlas. Psoriasis statistics: Prevalence. Accessed March, 2021. https://www.globalpsoriasisatlas.org/en/statistics.

THEME

Mental health, stigma and quality of life

Key insights

- Stress can act as both a consequence of psoriatic disease and a trigger for flare-ups. Yet it is rarely brought up during doctors’ appointments due to a lack of awareness among healthcare professionals and patients.
- Healthcare professionals must try to create opportunities in the conversation for someone with psoriatic disease to talk about how their illness affects them beyond the physical symptoms and, most importantly, patients should feel like they are being listened to.
- Taking a more holistic approach that includes not only the biological components of illness but also the psychosocial aspect, helps healthcare professionals understand the patient’s experience and improve multidisciplinary approaches to patient care.
- The problem of stigmatization is more nuanced than discriminatory looks in public spaces. Stigma also exists in health care and can be internalized by the person with the disease. Education about psoriatic disease for the public, the medical community and those affected is the best way to overcome this.
- Psoriatic disease and mental health are serious non-communicable diseases (NCDs). Disease areas in the health sector often operate in silos, so identifying psoriatic disease-related vulnerabilities, particularly mental health, can be overlooked. This can be overcome through better education, guidelines and communication with advocates in other disease areas for ideas and collaboration.

“I’d never had stress discussed in relation to my medical condition.”

Joel Nelson, United Kingdom

“I’m educating colleagues that the right approach starts with listening – a questionnaire is a good aid to embed this behavior.”

Professor Matthias Augustin, Germany

“There is a trend to stigmatize. Part of this is a natural reflex that comes from evolution. If someone looks different, then they pose a danger. At least, this is how stigma starts… We can overcome this with education.”

Professor Matthias Augustin, Germany

“People with mental health issues can live 10–20 fewer years.”

Alison Cox, United Kingdom

→ **See the roadmap action points, p.17**

THEME

Access to care through earlier diagnosis and better financing

Key insights

- Psoriatic disease is a multifactorial disease often accompanied by comorbidities. Diagnosing and treating comorbidities early is critical for better health outcomes and long-term cost savings.
- Patient associations must consider how to work with advocacy groups from other disease areas, for example those working on the broader NCD agenda and some of the more prominent diseases such as cancer, diabetes and mental health where there is a link to psoriatic disease. By working together across disease areas, opportunities exist to exchange ideas about better practices, pool expertise, extend messaging reach to gain attention on global health agendas and identify opportunities for funding by making psoriatic disease part of the story.
- People with psoriatic disease continue to face many unmet needs. In practice, clinical underestimation of psoriatic disease is common. Undertreatment persists, and people with psoriasis are often treated for extended periods with only topical drugs or traditional systemic therapies, despite the availability of effective and innovative treatments. Patient associations must advocate for people with psoriatic disease to have access to the right treatment, at the right time, with the right resources.
- Unequal access to care is evident everywhere, even within the same country. Patient associations must advocate to be involved in decision-making forums where they can fight for better and more equal access for all people with psoriatic disease.

"Unequal access to care in the same national territory persists. Everywhere."

Valeria Corazzo, Italy

"I believe we deserve the best treatment. Now's the time to ensure the right treatment, at the right time, with the right resources. This must be the commitment of the associations."

Valeria Corazzo, Italy

"We can present science that says people with severe psoriasis have a life expectancy seven years shorter than the general population, so that we can really put psoriasis and psoriatic diseases into the minds of the policymakers."

Lars Werner, Denmark

"Policymakers like everything to be simple and in grids and lines, and it's the advocates' job to show why we are relevant... we have to show how ourissues – NCDs –) are relevant to other existing global health priorities."

Alison Cox, United Kingdom

→ **See the roadmap action points, p.19**

THEME

Health workforce for better diagnosis and treatment

Key insights

- Health systems must embrace new models for diagnosing, treating, and managing care for people with chronic conditions.
- Patients with psoriatic disease may see their primary care physician several times a year compared with their dermatologist, who some patients rarely or never see. General practitioners (GPs) therefore play a central role in the continuous management of psoriatic disease and must be empowered with the knowledge to diagnose, treat effectively and manage patients with psoriatic disease.
- The person with psoriatic disease should share what they have learned through their own journey in managing their disease, to empower their GP, dermatologist and other patients.
- Shortages of healthcare professionals (HCPs) can lead to shorter consultation times. The HCP and patient alike may be keenly aware of time pressures. Primary care doctors or specialists may feel like they do not have enough time with the patient and, for various reasons, are powerless to change the situation. The person with psoriasis, on the other hand, may feel rushed and therefore be reluctant to mention issues they are having that seem trivial or are not directly related.
- Multidisciplinary teams need to coordinate patient-centric care better. This means better communication between specialist care experts. Enhancing dialogue between the care team can ensure everyone has the information to support the person needing care. Digital technologies can support communication between the person with psoriatic disease, their GP and their specialist care team, thereby helping to improve continuity and care coordination.
- Biosimilars offer the option of low-cost and effective treatments. Yet there has not been an uptake of these treatments. Now is an excellent time to change how we conceive of treating patients. Biologics and biosimilar options are available. Biosimilars can offer the option of low-cost and effective treatments if recommended by the specialist and agreed with the person receiving treatment.

> ***“What should be done is engaging family doctors and family medicine associations in conferences in continuing medical education programs… to talk about the issues of day-to-day treatment.”***
>
> Yochai Schonmann, Israel

> ***“There is so little emphasis on biosimilars. In many countries, in the Nordics, the United Kingdom, the Netherlands, and Germany, they deliver biosimilars, but not enough had happened in some parts of the world. Global organizations such as IFPA or IPC could come in and push on giving biosimilar to patients with psoriasis.”***
>
> Arnon Cohen, Israel

> ***“I’m a difficult patient, I had difficult symptoms and I didn’t fit any category. So that started my journey in trying to find a way how I can use that power of being a difficult patient to empower my dermatologist and the community.”***
>
> Ingvar Ingvarsson, Iceland

→ **See the roadmap action points, p.20**

THEME

Involving patients and their organizations in decision-making processes

Key insights

- Patients and their organizations should continuously be considered in developing policies and practices and should be involved in decision-making.
- Patient organizations are responsible for gathering greater knowledge and insights from people with psoriatic disease that can be shared with healthcare providers and pharmaceutical companies in order to improve the quality of care and treatment options available.
- Creating awareness about psoriatic disease is important in order to ensure that the disease is recognized within health decision-making forums as a priority. These forums provide a platform for advocating for improved access to treatment for psoriatic disease. They are also arenas where patient associations can campaign for financing or increased financial support for people with the disease and negotiate the cost of treatment. Financial support to improve early diagnosis and treatment should be regarded and positioned as an investment in health rather than as a financial burden.

> ***“The chief challenge is to get noticed. People need to know we’re here, and we need to be more visible.”***
>
> Forum participant

> ***“Data collection and evidence sharing on a vastly different scale would be a useful tool to elevate the psoriatic disease agenda.”***
>
> Forum participant

> ***“[As Pharma] What we ask from patient associations is to have an open mind to talk openly about the needs of patients and to make sure we have that trust we can build upon... We genuinely need to hear from patient associations worldwide as to what works.”***
>
> Rajesh Gupta, UCB

→ **See the roadmap action points, p.22**

THEME

Digital transformation and using telemedicine to improve care

Key insights

- Greater digital communication between specialist care, the GP and the patient could improve access to care by providing more efficient virtual appointments and teledermatology services for people who may live in remote areas or have challenges that prohibit them from easily attending in-person consultations.
- While telemedicine can lead to more frequent, efficient and accessible appointments, considerations about how this could be approached should incorporate patients' concerns and should maintain the same standard of care as in-person appointments. Consideration should be given to when digital consultation is not appropriate.
- Digital consultations may work well for a portion of society. However, some groups who are not digital natives, such as older citizens and people without easy access to relevant technology, may be shut out if services migrate to digital platforms. Frameworks need to be in place to ensure data, images, and notes are secure and private, and these frameworks should apply to the health system and private doctors or dermatologists.

> ***"There's a huge disparity in rural and urban capacity, and that feeds strongly into the patient experience – telemedicine may be a way or a step towards equalizing rural capacity."***
>
> Masanori Okuse, Japan

> ***"Dermatologists do not necessarily need to touch and feel. Securely submitted photos could work well if the photography or video is clear enough."***
>
> Forum participant

> ***"It's all about who owns the data and the information about me."***
>
> Ingvar Ingvarsson, Iceland

> ***"You really need to get the 'how' right. Telemedicine needs a real purpose, and the patients must feel that their feedback is driving the decisions."***
>
> Forum participant

→ **See the roadmap action points, p.23**

Best practices and resources

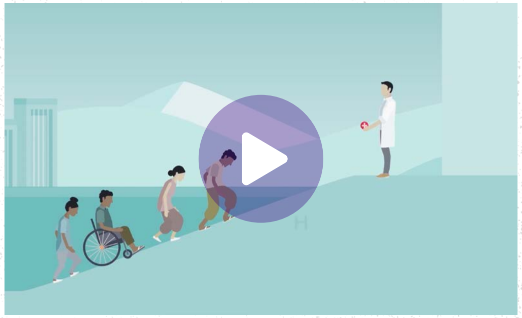
Best practice

Advocating for a person-centered approach in clinical appointments

Patient advocates play an important role in providing a personal perspective on their experience as a person living with psoriatic disease. They can help create an emotional connection with an audience by using their story to highlight topics such as mental health.

At the Forum, Joel Nelson, an IFPA ambassador living in the United Kingdom, brought the concepts and statistics of psoriatic disease to life, by explaining the inextricable link between psoriatic disease and mental health. For Joel, mental health issues always lead to a flare-up, such as limited mobility or chronic pain. Stress is a significant trigger.

Over the years, Joel has learned to see the link between his disease and mental health, and now he speaks with his doctor about stress during appointments. People living with the disease should be empowered to recognize the triggers and how their disease can affect their mental health to enable them to open up discussions with their healthcare providers. Patient associations can support patients and healthcare providers with information and advice on how to communicate on this issue.



View World Health Organization video: What is Patient-Centred Care?

> ***"It's only in the last two, three years that I've started understanding how it's all linked. Doctors need to treat the person, not the rash they see."***
>
> Joel Nelson, UK

Best practice

Unpacking how the **Healthier Together – EU Non-Communicable Diseases Initiative** can support actions to improve life for people living with psoriatic disease

Funding opportunities for health are available for countries within the EU to access, and recently there has been unparalleled support for NCDs. In 2021, the European Commission launched Healthier Together – EU Non-communicable disease initiative “to support European Union (EU) countries in identifying and implementing effective policies and actions to reduce the burden of major NCDs and improve citizens’ health and well-being”.[1] The initiative will run from 2022 to 2027.

The focus of the initiative is on health promotion and disease prevention. This requires knowledge production, health data collection, and improvement of early detection.

The initiative also recognizes the inequity of access to care and has a flexible approach to country-specific needs.[1]

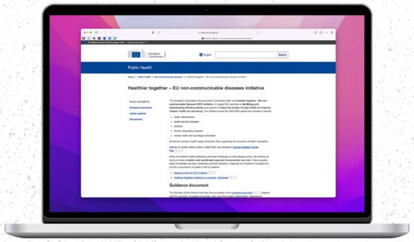
EU4Health

The EU4Health program is an EU commitment to health as an investment with a €5.3 billion budget (2021–27). In response to the COVID-19 pandemic, this is “unparalleled EU financial support in the health sector” that will allow for impactful projects for sustainable change.[2] Of this budget, at least 20% has been committed to health promotion and disease prevention.[3]

It is up to Member States of the EU to apply for funding in areas and actions they want to be part of.

Patient associations can approach their local councillors, make them aware of funding opportunities and demonstrate how psoriatic disease can be linked in.

The European Commission has also established the Health Policy Platform, an interactive tool to boost discussions about public health concerns and share knowledge and best practices that patient associations can access to exchange with others, pool expertise in joint statements and disseminate actions among a wide audience.



Learn more about the Healthier Together – EU NCD Initiative

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1. Directorate-General for Health and Food Safety EC. Healthier together EU Non-Communicable Diseases Initiative, June 2022. https://health.ec.europa.eu/publications/eu-non-communicable-diseases-ncds-initiative-guidance-document_en. Published 2022. Accessed June 2022. **2.** Directorate-General for Health and Food Safety EC. EU4Health programme 2021-2027 – a vision for a healthier European Union. https://health.ec.europa.eu/funding/eu4health-programme-2021-2027-vision-healthier-european-union_en. Published 2021. Accessed September 2022. **3.** Directorate-General for Health and Food Safety EC. The EU’s ‘Healthier Together’ Non-Communicable Diseases Initiative, Reducing the burden of non-communicable diseases. https://health.ec.europa.eu/system/files/2022-07/ncd_initiative_factsheet.pdf. Published 2022. Accessed September 2022.

Better practice

Telehealth policy principles

The National Psoriasis Foundation, as part of a network of 35 patient advocacy organizations in the United States, has developed principles for telehealth policy.

The organizations acknowledge that the COVID-19 pandemic highlighted the important role of telehealth, encouraging the development of new ways to continue to deliver timely and safe healthcare treatments when in-person visits were not possible.

Looking forward, the 35 organizations believe that telehealth could be key to improving health and well-being in the United States.

The six principles are presented as a guide for policymakers to ensure telehealth is affordable and accessible for all:

1. Improving Access through Equitable Coverage
2. Improving Access through Easing Technology Barriers
3. Preserving and Promoting Patient Choice
4. Removing Geographic Restrictions
5. Protecting Patients and Provider Legal Rights
6. Increasing the Evidence Base for Telehealth

The policy principles offer inspiration to patient organizations in Europe seeking to ensure better integration of telehealth as part of healthcare provisioning.

Read the Principles for Telehealth Policy

Resources available for patient associations

European Commission

EU Health Policy platform

The virtual platform provides a place for local organizations to connect; the idea is for organizations to meet once or twice a year to discuss working actions and get feedback.

Healthier Together – EU Non-Communicable Diseases Initiative

The European Healthier Together Initiative consists of five strands aimed at reducing the burden of NCDs. The five strands include health determinants, cardiovascular diseases, chronic respiratory diseases, and mental health and neurological disorders.

Healthier Together – EU Non-Communicable Diseases Initiative guidance document

As a first step, a guidance document has been co-created involving competent authorities, input from health stakeholders, international organizations and various Commission departments. The document is to help guide policies and sets up a basis for implementation of actions over the next few years.

NCD Alliance

2022 Global Week for Action on NCDs campaign

The annual Global Week for Action on NCDs seeks to ensure that NCD prevention and management get the attention and action they deserve, everywhere, for everyone. In 2022, the focal priority was the urgent need for increased NCD financing to prevent and treat NCDs and build resilient health systems that leave no one behind. Key campaign resources are available to help individuals and organizations to mobilize on the issue of severe underfunding of NCDs.

Advocacy Toolkit on NCDs in Post-2015 Development Agenda

The toolkit aims to equip advocates with the information and resources necessary to ensure the inclusion of NCDs and health in the Post-2015 Development Agenda.

World Health Organization

What is Patient-Centred Care?

The World Health Organization has compiled an explanatory video on patient-centred care, a concept that promotes designing health systems around the needs of people instead of around diseases and health institutions, so that everyone gets the right care, at the right time, in the right place.

IFPA

IFPA Forum resources

A link to the video from the Forum and various resources, including the briefing book as well as the links and tools mentioned at the Forum, are hosted on the IFPA website.

IFPA Mental Health resources

IFPA has written a report and gathered resources to identify and summarize the link between mental health and psoriatic disease.

IFPA position statement: Biosimilars

IFPA welcomes the introduction of safe and effective biosimilars that have the potential to improve access to treatment and increase treatment options for people living with psoriasis.

National Psoriasis Foundation

Coalition on telehealth

In the United States, a coalition of organizations came together under the precept that telehealth can and should be used to increase patient access to care. These organizations stand ready to work with Congress to permanently integrate telehealth into legislation.

A roadmap to guide action

The roadmap detailed in the following pages provides a framework for patient associations in Europe – and in other parts of the world – to use as a source of inspiration when conceptualizing local priorities and aligning them with a broader global agenda seeking to promote improved care for people with psoriatic disease.

This section consists of:

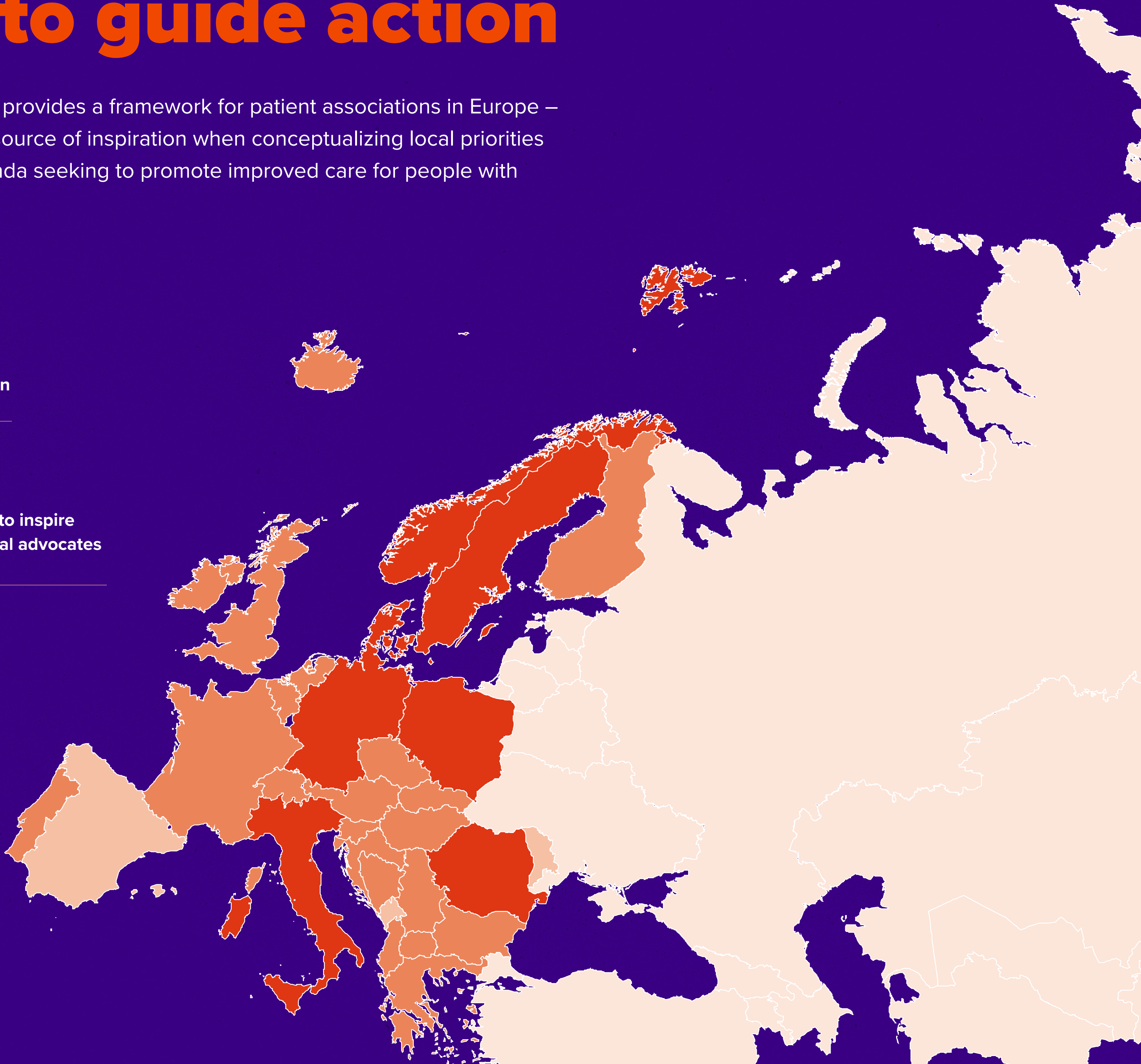
Five
themes

15
actions proposed for prioritization

54
examples of tactics provided for patient associations to inspire local patient association representatives and individual advocates

Percentage of adults estimated to be living with psoriasis in countries across Europe[1]

⬜ 0-≤ 1.0%
🟨 1-≤ 1.5%
🟧 1.5-≤ 2.0%
🟥 ≥ 2.0%



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[1] Global Psoriasis Atlas. Psoriasis statistics: Prevalence. Accessed March, 2021. https://www.globalpsoriasisatlas.org/en/statistics.

Roadmap actions

Improving mental health, reducing stigma and increasing quality of life

Our demands	Tactics for meeting our demands
Mental health needs more recognition and prioritization. Advocate for a bigger conversation on mental health across the healthcare sector and the breakdown of departmental silos that prevent a patient-centred approach to care.	• Engage with stakeholders across the healthcare sector on the topic of mental health and psoriatic disease, to advocate for increased funding for NCDs. • Provide educational material about mental health to people living with psoriatic disease and other stakeholders, so they are educated to recognize the impact of the disease on mental health alongside the physical, social and emotional impact. • Advocate for recognition and prioritization through greater funding for NCDs and mental health by writing to national or EU policymakers.
Stigmatization of people with psoriatic disease must be reduced. Aim to raise the level of awareness of psoriatic disease among the public and help to dispel misconceptions that could lead to discrimination.	• Communicate clearly about psoriatic disease. Typical messaging could reassure people that it is not contagious. • Empower patients to raise mental health concerns and to avoid self-stigmatization. Collect and share people's stories in different formats –, ideas could include a short publication or use patient quotes and images via social media. • Create a template that can be used by associations to write to local journalists and conduct training for patient advocates that includes education on the use of stigmatizing language.
A people-centred approach to psoriatic disease management must be adopted. Promote the use of a holistic approach to clinical care that systematically considers the biological, psychological, and social factors and their complex interactions.	• Develop a position paper and advocate at national level for health systems to adopt and put in practice a person-centred care model for the treatment of psoriatic disease. • Use meeting platforms and communication channels for engaging with HCPs directly on facilitating an approach that considers individual therapeutic needs. • People with psoriatic disease may lack agency in making treatment decisions and may be overwhelmed by treatment and management decisions. Capacitate them to play a more active role in decision-making in their treatment.

Our demands	Tactics for meeting our demands
A better understanding of the link between mental health and psoriatic disease is needed. Raise the level of awareness of people with psoriatic disease and HCPs regarding how to address the issue of mental health in clinical settings.	• Request that patients fill out a questionnaire (a physical or digital form) prior to their medical appointment, to avoid limited time at appointments being an obstacle to discussing mental health. The form should include questions on mental well-being. This will ensure that patients are well prepared and also know what to prioritize during the allocated consultation time. • Develop materials or cue cards to help HCPs effectively manage their time in appointments, to support their communication with patients. The materials can prompt or remind HCPs of specific questions to ask during clinical appointments regarding mental health topics such as stress. • Encourage HCPs to ask whether patients have brought any questions with them or whether there is anything else they want to mention. • Provide guidance for HCPs on addressing issues around mental health and psoriatic disease, so that they are aware of what questions to ask. • Create a certified “psoriatic disease volunteer” course that addresses the subject of mental health.

Roadmap actions

Improving access to care through early diagnosis and better financing

Our demands	Tactics for meeting our demands
More data and real-world evidence about the benefits of access to different treatments must be generated. Drive efforts for improved data collection on the treatment of people with psoriatic disease.	• Encourage the systematic collection of routine data on all aspects of the disease, including treatment and real-world studies on their application, and use these research insights to advocate for improved access to treatments. • Support qualitative research and surveys on patient perceptions and experiences of treatment types that can also be communicated back to healthcare providers and the pharmaceutical industry. • Make a list of available funding opportunities and when applications are required, and make this information available to research community contacts.
Multidisciplinary treatment for people living with psoriatic disease can support better management of the disease and detection of comorbidities. Encourage the development and use of clinical guidelines on the management of psoriatic disease and aid in early diagnosis.	• Help support research on the use of a multidisciplinary care approach to psoriatic disease, to substantiate and promote its use. • Work together with other NCD patient associations, to advocate for multidisciplinary approach to treatment. • Build relationships with stakeholders in healthcare to advocate for and provide input from the patient perspective in the development of clinical guidelines. Help ensure the guidelines are adopted at national level or, if already in place, that they are updated as necessary. • Advocate for and support knowledge sharing on comorbidities of psoriatic disease so that they are detected and treated in good time, given that people with psoriatic disease are at higher risk for developing other illnesses.
Patient associations have an important role to play and must work with other groups active within psoriatic disease and across other disease areas to make an impact. Establish common ground with other organizations, gather and share learnings and better practices on advocating for improved access and financing.	• Identify issues and advocacy partners to work with on collaborative agendas, to create a knowledge-sharing and advocacy network. • Ensure that patient association representatives are invited to attend and engage with medical societies at meetings, and that they are listened to, because patient associations have a powerful voice in representing people with psoriatic disease. • Identify existing health and policy platforms and communities where the patient association can participate and speak up. • Collaborate with other NCD organizations and determine whether they have a pathway for securing funding from initiatives such as the Healthier Together – EU Non-Communicable Diseases Initiative. • Contact a policymaker and campaign for funding allocations to projects from supranational funding pools.

Roadmap actions

Improving the health workforce for better diagnosis and treatment

Our demands	Tactics for meeting our demands
General practitioners must be educated about psoriatic disease. Highlight the need for increased training in dermatology as part of tertiary education and encourage the continued medical education of HCPs.	• Establish what the needs are among local GPs with regard to dermatological training, for example by conducting an online survey or speaking with medical associations. • Raise awareness among medical societies and on other national platforms about the information and training required, based on the educational needs of GPs in your country.. • Work with partners to develop training materials and provide continued medical education courses or workshops to HCPs.
Shared decision-making between providers and patients should guide treatment choices. Determine the gaps in treatment and the needs of patients, and establish advocacy approaches suited to your situation.	• Identify and map what treatments – including biologics and biosimilars – are available and how much they cost. • Compare access to treatments with other markets. If a treatment is not available in a country, try to find out why and what is preventing its availability. This will help steer advocacy efforts. For example, it could be a regulatory challenge or funding challenge or lack of demand or awareness of the product locally. Alternatively, government authorities may not have tried or could have failed to negotiate a suitable cost to guarantee its availability. • Encourage and support research initiatives if there are safety concerns, a lack of awareness or cost challenges. • Leverage the research in order to advocate at national or regional level for the use of biosimilars in local markets. • Consider whether raising the profile of biosimilars or biologics as a category is part of a broader conversation that should involve other disease areas, and issue a joint statement on the use of biosimilars or biologics in your country or region.

Our demands	Tactics for meeting our demands
Good communication is critical. Bridge the communication gap between the patient, GP and specialist. Seek solutions to improve communication between members of the care team and the patient.	• Speak with patients and HCPs in your country in order to understand the communication challenges. • Raise awareness of the challenges with health care providers and, where possible, offer suggestions for how these could be addressed, for example via digital technologies or changes to existing information systems.
Patient involvement and responsibility are important aspects of care, and shared decision-making must be encouraged. Ensure that patients are informed and enabled to participate in decisions that are relevant to them.	• Empower patients to speak about their symptoms and condition. Inform and educate the person receiving treatment on ways to speak up for themselves at clinical appointments and be proactively involved in treatment decisions. • Create a space, such as an online forum, where patients can access information and share their experiences. • Patient associations must make GPs aware of the presence, support, and motivation they can offer patients, and motivate GPs to refer newly diagnosed patients to the patient association. • Point out research needs and how a person with psoriatic disease can participate in research aimed at improving the safety, efficacy and use of treatments, in response to increasing calls from health regulators for the patient perspective in clinical trials.

Roadmap actions

Involving patients and their organization in decision-making processes

Our demands	Tactics for meeting our demands
Patient organizations must be part of the policy-level decision-making process. Advocate for patient inclusion at all levels of decision-making.	• Work to raise the profile of your patient association to ensure a presence in spaces where discussion and decision-making around health, and specifically psoriatic disease, take place. For example, national, regional and international forums, medical conferences, medical associations and regulatory boards. • Identify ways to increase collaboration between patient organizations to strengthen your association’s capacity to participate in different decision-making forums. • Support ambassador programs and train/empower more patients to become advocates. • Ensure availability of clinical guidelines that are operationalized, make sure the patient perspective is integrated in guidelines.
All NCD patient associations, including psoriatic diseases organizations, must advocate for greater investment in NCDs. Develop a case for greater investment.	• Collaborate with theNCD Alliance to build a strong case, and use this as an advocacy tool to make the case for increased investment. • Build a network and collaborate with patient organizations and other stakeholders, such as the private sector and pharmaceutical companies, to coordinate advocacy for greater investment in NCDs.

Roadmap actions

Digital transformation and using telemedicine to improve care

Our demands	Tactics for meeting our demands
Models integrating telehealth should be considered in order to improve access to specialist care. Recommend that telemedicine/digital health be added to the core content of health education and professional training programmes, and that investment be made in digital capacity and technologies.	• Governments should support the uptake of telemedicine by setting up a sustainable infrastructure for ease of access. Patient organizations should write to policymakers. • Advocate for the proficiency of HCPs in the use of digital technology to be raised within the clinical setting, to ensure the long-term care of patients with psoriatic disease. • Offer to provide patients with education and training in the use of teledermatology, to improve their awareness, perceptions and ability, and to help facilitate its uptake.
A protocol for the use of digital technology which reflects the desires and concerns of the patients must be established. Address issues of privacy and security.	• Establish the extent to which telemedicine is used and what forms of regulation are in place to monitor its use. Contact other disease organizations to identify where telemedicine is currently being used and whether there is a need or opportunity to collaborate on the development of a guidance document or campaign for legislation integrating teledermatology services to be included or amended. • Consult with patients about their concerns regarding telemedicine and establish ways in which these concerns can be appropriately addressed. • Encourage patient associations to voice concerns with the healthcare sector about digital transformation, i.e. concerns regarding privacy and confidentiality. • Read and share the National Psoriasis Foundation telehealth policy principles to educate patients about the benefits of telemedicine, and consider how these policies could be evolved and applied in national contexts in Europe. • Work with other patient associations to develop recommendations for a protocol, and lobby for its use.