IFPA
FORUM
EUROPE 2022

Navigating the playbook

IFPA Europe Action Playbook

Guidance and tools to support patient advocates to take action on the IFPA Forum Europe 2022 roadmap

IFPA is the international federation of psoriatic disease associations. Together, with our members in Europe we advocate for a future where all people living with psoriatic disease enjoy good health and wellbeing, free from stigma and preventable disability and comorbidities.

Navigating the playbook

- A playbook with tools for action
- Getting started
- WHO resolution and recommendations on psoriatic disease
- Addressing psoriatic disease within a comprehensive NCD response
- Five key recommendations for patient associations in Europe
- Thematic action areas
- Tools and resources

A playbook with tools for action

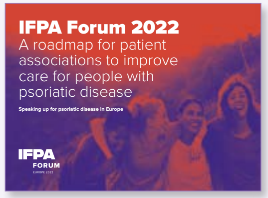
Why a playbook?

This Playbook offers practical assistance to advocates and members of patient organizations in their efforts to raise awareness and recognition of psoriatic disease as a significant health issue that requires enhanced treatment and care.

It aims to:

- Inspire action on the *IFPA Forum Roadmap Europe* recommendations
- Provide quick-and-easy access to relevant tools and resources
- Offer helpful guidance or advocacy tips

Tran Hong Truong, PsorViet and Josef De Guzman, PsorPhil and IFPA, IFPA Forum Europe, 2022



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

A Roadmap identifying regional priorities

The *IFPA Forum Roadmap Europe* was developed to guide patient association members and advocates in driving policy action. The roadmap is a cross-sector collaborative effort that draws on insights and input from psoriatic disease patient associations, public health actors, and the pharmaceutical industry to formulate specific recommendations.

The recommendations are aligned to five themes determined as priority areas for mobilizing action in Europe.

IFPA FORUM
IFPA Europe Action Playbook

Moving to action

This Playbook seeks to assist patient association members when formulating local, context-specific action plans. Like the *IFPA Forum Roadmap Europe*, the Playbook is structured around five themes. Using the same thematic structure, the playbook bridges the roadmap recommendations and available tools/resources for each thematic area. It aims to help advocates translate the roadmap recommendations into actionable steps with a suite of digital and physical tools. Use the playbook to find tools, resources and advocacy tips to support engagement when planning advocacy activities.

Getting started

IFPA has united the global psoriatic disease community to fight for improved recognition and prioritization of the condition on the health agenda. It is spearheading change globally and at the regional and national levels. In doing so, IFPA has built up a rich store of information, advice and tools on its website. A wealth of knowledge has also been shared at the IFPA Forum Europe held in 2022 and through speaking with IFPA patient association members.

This playbook adds value to IFPA members by creating a convenient and user-friendly digital repository of tools and resources for action.

Speaking with different audiences

The playbook provides tools and resources that may be used when planning advocacy initiatives and communicating with a broad range of stakeholders. Use the icons to help identify the relevant audience for a particular tool or resource.

Priority actions for each theme

The *IFPA Forum Roadmap Europe* introduced prioritised targets for united action. In each section of this playbook, where the themes are presented, recommendations or targets are prioritised for united action. Here, you can find resources and tools selected or explicitly designed to assist your advocacy and reach the targets.

Quick icon navigation

- Advocacy tip
- Tool to download and adapt
- Resource document to read
- Video to watch

The audience materials can be used for

- People with psoriatic disease
- Patient association or civil society
- Governments and policy makers
- Health care professionals
- Academic researchers
- The media

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WHO resolution and recommendations on psoriatic disease

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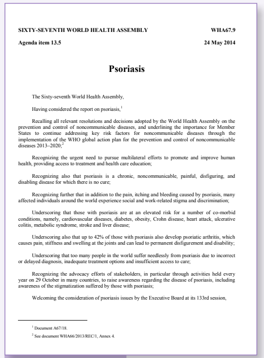
WHO resolution and suggestions on psoriatic disease

The World Health Organization (WHO) leads the way in discussing and addressing global health issues. They have created two important documents shown below that guide conversations and actions related to psoriatic disease.

Camille Lancelot, IFPA and Guillermo Gutierrez, Fundapso, Colombia
IFPA Forum Europe, 2022



SIXTY-SEVENTH WORLD HEALTH ASSEMBLY **WHA67.9**
Agenda item 13.5 **24 May 2014**

Psoriasis

The Sixty-seventh World Health Assembly,

Having considered the report on psoriasis,[1]

Recalling all relevant resolutions and decisions adopted by the World Health Assembly on the prevention and control of noncommunicable diseases, and underlining the importance for Member States to continue addressing key risk factors for noncommunicable diseases through the implementation of the WHO global action plan for the prevention and control of noncommunicable diseases 2013–2020;[2]

Recognizing the urgent need to pursue multilateral efforts to promote and improve human health, providing access to treatment and health care education;

Recognizing also that psoriasis is a chronic, noncommunicable, painful, disfiguring, and disabling disease for which there is no cure;

Recognizing further that in addition to the pain, itching and bleeding caused by psoriasis, many affected individuals around the world experience social and work-related stigma and discrimination;

Underscoring that those with psoriasis are at an elevated risk for a number of co-morbid conditions, namely, cardiovascular diseases, diabetes, obesity, Crohn disease, heart attack, ulcerative colitis, metabolic syndrome, stroke and liver disease;

Underscoring also that up to 42% of those with psoriasis also develop psoriatic arthritis, which causes pain, stiffness and swelling at the joints and can lead to permanent disfigurement and disability;

Underscoring that too many people in the world suffer needlessly from psoriasis due to incorrect or delayed diagnosis, inadequate treatment options and insufficient access to care;

Recognizing the advocacy efforts of stakeholders, in particular through activities held every year on 29 October in many countries, to raise awareness regarding the disease of psoriasis, including awareness of the stigmatization suffered by those with psoriasis;

Welcoming the consideration of psoriasis issues by the Executive Board at its 133rd session,

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[1] Document A67/18.

[2] See document WHA66/2013/REC/1, Annex 4.

Resolution on psoriasis

In 2014, a resolution on psoriasis was adopted by the 67th World Health Assembly 2014 (WHA 67.9). The resolution signalled that the WHO member states recognised psoriasis as a serious non-communicable disease.

Resource

Global report on
PSORIASIS
World Health Organization

Global report on psoriasis

In 2016, the WHO developed a Global report on Psoriasis with recommendations for actions for governments, policymakers, health systems and health professionals, patients organizations and civil society.

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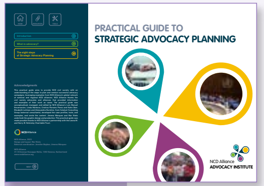
Addressing psoriatic disease within a comprehensive NCD response

Psoriatic disease is a non-communicable disease (NCDs). Therefore, this group of conditions should be included as part of a global response to NCDs. The United Nations Sustainable Development Goals has a specific target for reducing mortality on NCDs, which is to reduce by one-third the premature deaths from NCDs in the coming years.

People with psoriatic disease often live with other comorbid NCDs. Therefore, important overlaps in response are required to address psoriatic disease, mental health, cardiovascular disease, diabetes, and other comorbid NCDs. By expanding the understanding of the risks for and scope of NCDs, opens the door to working with other disease areas to achieve shared goals for greater impact.



A practical guide to strategic advocacy planning

The NCD Alliance, a civil society network, dedicated to preventing and controlling NCDs has put together a practical guide that aims to strengthen NCD civil society advocacy efforts to drive transformative change at the global, regional and national levels.

Resource


Valeria Corazzo, APIAFCO, Italy and Nati Pareja, Acción Psoriasis, Spain
IFPA Forum Europe, 2022

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Five key recommendations for patient associations in Europe

In 2022, patient associations, health care professionals, and representatives from the private sector came together to discuss a *IFPA Forum Roadmap Europe* for proactively moving the agenda on psoriatic disease forward in Europe.

Several key recommendations were made to improve care for people living with psoriatic disease in the region. The full-text recommendations can be found in the *IFPA Forum Roadmap Europe*. Below the recommendations are converted into actionable statements.

Mental health

Expand mental health care provision to people with psoriatic disease and ensure it is delivered through a person-centred approach.

Multidisciplinary care team

Expedite access to multidisciplinary care where a team of specialists provide comprehensive care based on the needs of the patient.

Integrated care models

Integrated models of care informed by patient experience, including clear referral pathways, will increase the quality care received by people with psoriatic disease.

Shared decision-making

Increase patient involvement in the care decision-making process.

Digital health and telemedicine

Deploy digital health and telemedicine to improve gaps in care safely.

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- Mental health, stigma, and quality of life
- Access to care through earlier diagnosis and better financing
- Health workforce for better diagnosis and treatment
- Involving patient associations and their members in decision-making
- Digital transformation and telemedicine to improve care
- Putting the playbook into action
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Mental health stigma, and quality of life

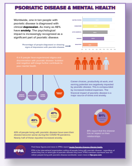
Psoriatic disease and mental health are intricately linked. The emotional distress and mental health impact of psoriatic disease can be as severe as the experience of physical symptoms.

Discrimination, stigmatization, and further psychological harm often affect a person's quality of life.

How to take action:

Promote better understanding of the link between mental health and psoriatic disease

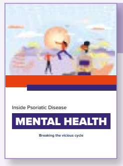
Psoriatic disease & mental health statistics



An infographic showing the connection between psoriatic disease and psychological impacts including depression, anxiety and isolation.

Resource

IFPA Mental health and psoriatic disease toolkit

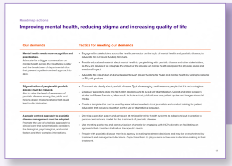


A digital library with reports, statistics, news, tools and resources to help build your case.

Tool

Ensure mental health gets more recognition and is prioritized

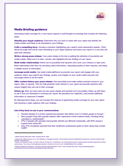
Core mental health priority areas



Demands and tactics from the Roadmap for advocacy and engagement planning.

Resource

Media story for pitching locally



A how-to guide to creating a media story, including a template and journalist pitch.

Tool

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A playbook with tools for action

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Mental health, stigma, and quality of life

Access to care through earlier diagnosis and better financing

Health workforce for better diagnosis and treatment

Involving patient associations and their members in decision-making

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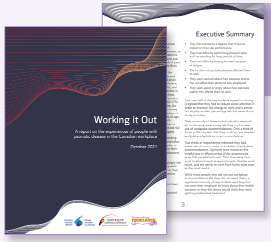
How to take action:

Eliminate the stigmatization of people with psoriatic disease

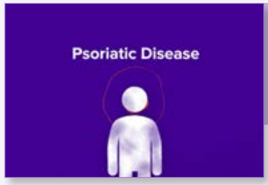
Working it out



The Canadian Psoriasis Network (CPN), the network Unmasking Psoriasis and the Canadian Association of Psoriasis Patients (CAPP) report on the experiences of people with psoriasis in the workplace (available in English and French).

Resource

Awareness-raising video of the mental health impacts of psoriatic disease



Use this short video when you want to introduce the issues which drive poor mental health.

Video

Encourage a person-centred approach to psoriatic disease management

What is people-centred care?

A film by WHO on the importance of informing, consulting, and listening to patients. Show the film to prompt discussion with stakeholders.

Video

Joel Nelson

@JoelvsArthritis 2,67 mil subscritores 118 vídeos

On a mission to raise awareness and support those living with chronic ilne...

Why I Advocate & Our Channel's Mission

An introduction to me, my arthritis journey, how I found my voice and why I've taken to YouTube to raise awareness of arthritis, autoimmune disease and chronic illness.

This video also gives you a little indication of what Content you can expect on this Channel.

The Chronic Pain Club Talk Show

Starting conversations to change lives, The Chronic Pain Club Talk Show exists to amplify the patient voice and promote the value of lived experience. We aim to inspire, educate and remove th...

Advocating on digital platforms

Joel is a passionate psoriatic disease and arthritis advocate who uses his story to inspire change.

With the onset of inflammatory arthritis at just 10 years old and skin manifestations of psoriatic disease in his 20s, Joel has experienced the physical, aesthetic, and mental health impacts of psoriatic disease for most of his life.

In his early 30s, he decided to raise his voice and harness his experience to help others. He campaigns actively for awareness and change, focusing on psoriatic disease, juvenile idiopathic arthritis, and mental health. His goal is to stop the stigma around these diseases and help others feel less alone. Joel has channels on the game streaming site Twitch and YouTube and his podcasts are available on all major platforms.

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Access to care through early diagnosis and better financing

There is no cure for psoriatic disease, but multiple treatments are available to manage the disease effectively. People with psoriatic disease can be spared the suffering caused by this common and complex condition. It is possible to change the prospects of people living with psoriatic disease by dismantling the barriers to early and effective treatment.

How to take action:

Find ways to encourage the generation of data and real-world evidence about the benefits of access to different treatments

Real-world research study

An example of a real world study on people with psoriasis and biological therapy.

Resource

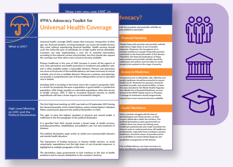
Advocate for a multidisciplinary approach in caring for people living with psoriatic disease to support better managing the disease and detecting comorbidities

White paper on Universal Health Coverage (UHC)

White paper outlining the discussion on psoriatic disease and UHC.

Resource

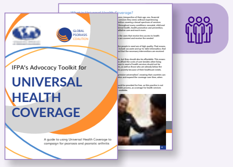
Factsheet on Universal Health Coverage



An Introduction to UHC and how UHC themes can be used to advocate for psoriasis and psoriatic arthritis.

Resource

IFPA advocacy toolkit for Univeral Health Coverage



A guide to using UHC to campaign for psoriasis and psoriatic arthritis.

Tool

Letter to a politician or Ministry of Health with clear ask for (selectable) themes

A letter template on the Roadmap themes to adapt and use.

Tool

Navigating the playbook

How to take action:

Encourage collaboration between patient associations and others, including groups within psoriatic disease and other relevant disease areas

Healthier together – EU non communicable diseases initiative

Use the EU initiative guidance document to help guide and coordinate action on NCDs, and identify or create windows of opportunity for high-impact actions related to advocacy on psoriatic disease and NCDs.

Resource

Part A – The Healthier Together Initiative in a nutshell

In December 2021, the European Commission launched the Healthier together – EU Non-Communicable Diseases Initiative (EU NCD Initiative), to support EU countries in reducing the human and financial burden of non-communicable diseases (NCDs). The Initiative hence helps

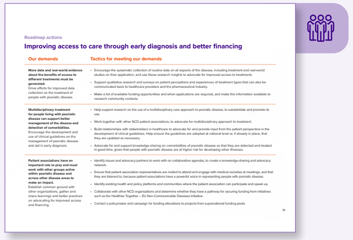
Healthier Together
EU Non-Communicable
Diseases Initiative

June 2022

Core access to care areas

Demands and tactics from the Roadmap for advocacy and engagement planning.

Resource



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.

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Become part of the broader Universal Health Coverage discussion

The political declaration on UHC is a new instrument in IFPA's toolkit that can be used to advocate for people living with psoriatic disease. The toolkit includes advice for lobbying politicians and health ministries on vital topics:

- Access to medicines
- Health workforce preparedness and presence
- Financial costs of living with psoriatic disease
- Disabilities related to psoriatic disease
- Person-centered model of care and comorbidities including mental health.

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A playbook with tools for action

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Mental health, stigma, and quality of life

Access to care through earlier diagnosis and better financing

Health workforce for better diagnosis and treatment

Involving patient associations and their members in decision-making

Digital transformation and telemedicine to improve care

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Health workforce for better diagnosis and treatment

Psoriatic disease requires lifelong care, monitoring, and continuous management. Treatment quality and disease management depend on the accessibility and availability of the health workforce. The shortage of health care workers poses an existential threat to public health systems and real possibilities of unmet needs for people living with psoriatic disease.

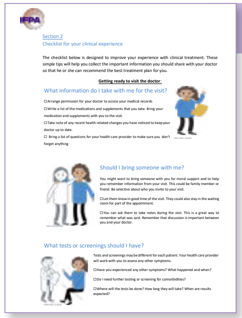
How to take action:

Embed shared decision-making between providers and patients to guide treatment choices

Checklist for your clinical journey

Simple tips to help people with psoriatic disease collect and prepare information to share with doctors and specialists.

Tool



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Section 2

Checklist for your clinical experience

The checklist below is designed to improve your experience with clinical treatment. These simple tips will help you collect the important information you should share with your doctor so that he or she can recommend the best treatment plan for you.

Getting ready to visit the doctor:

What information do I take with me for the visit?

☐ Arrange permission for your doctor to access your medical records

☐ Write a list of the medications and supplements that you take. Bring your medication and supplements with you to the visit.

☐ Take note of any recent health-related changes you have noticed to keep your doctor up to date.

☐ Bring a list of questions for your health care provider to make sure you don't forget anything

Should I bring someone with me?

You might want to bring someone with you for moral support and to help you remember information from your visit. This could be family member or friend. Be selective about who you invite to your visit.

☐ Let them know in good time of the visit. They could also stay in the waiting room for part of the appointment.

☐ You can ask them to take notes during the visit. This is a great way to remember what was said. Remember that discussion is important between you and your doctor.

What tests or screenings should I have?

Tests and screenings may be different for each patient. Your health care provider will work with you to assess any other symptoms.

☐ Have you experienced any other symptoms? What happened and when?

☐ Do I need further testing or screening for comorbidities?

☐ Where will the tests be done? How long they will take? When are results expected?

Improve HCP education and training about psoriatic disease

The GPP Charter

GPP CHARTER

The GPP Charter defines a collaborative approach to identifying common goals with the aim to enable people living with generalized pustular psoriasis (GPP) the freedom to live the life they choose.

The purpose of the Charter is to unite the community living with, and working for, GPP under a set of agreed principles to improve and change the current status quo. Through the co-creation of this Charter, the views from multi-stakeholder perspectives have been considered to ensure a consistent and effective call to action for positive change across all sectors of society.

The Charter takes into consideration how GPP, a rare autoinflammatory skin disease, can have both a physical and emotional impact on people living with the condition. Outlined below are the steps set out to call for and make this positive change and maintain momentum in driving GPP up the agenda.

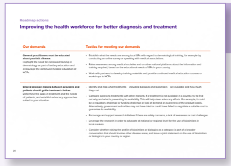
AGREED CALLS TO ACTION:

1. Increase GPP awareness as a rare, unpredictable, and life-threatening autoinflammatory, systemic disease that is distinct from plaque psoriasis.

A multi-stakeholder document that sets out the steps to call for change to the current status quo around generalized pustular psoriasis (GPP) and build momentum in driving GPP up the agenda.

Tool

Core health workforce priorities



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.

20

Demands and tactics from the Roadmap for advocacy and engagement planning.

Resource

Bridge the communication gap between the patient, GP and specialist

Medical appointment guide

A checklist and engagement guide that prompts patients to solicit pre-session notes to ensure all concerns get voiced and heard.

Tool

psoriasisSPEAKS

YOUR APPOINTMENT GUIDE

Need help starting a conversation with your doctor? Start below.

Create Your Goal Statement

What treatment options might help me reach these goals?

Where my plaques are located:

How to take action:

Encourage patient involvement and responsibility in shared decision-making

Meeting-in-a-box for roundtable or one-on-one

Lead an engagement meeting with meeting purpose, key message toolkit, sample agenda example, and conversation prompt cards.

IFPA

Planning a meeting or workshop for stakeholders

This **meeting-in-a-box tool** aims to support patient associations in preparing for a meeting with critical stakeholders that aligns local priorities with the themes from the **IFPA Europe Roadmap** and drives engagement with stakeholders.

Tool

Tell doctors about the medical appointment check-list

Giving patients a checklist is a great way to get them to plan for their appointment and ensure they get the information they need and that their concerns are brought to their doctor's attention. However, it is also a good idea to tell health care providers about the checklist so that they can ask the patient whether they have prepared questions on what they would like to talk about at the consultation. Doctors are precious allies for patients: the doctor can help spread the checklist so that other patients can benefit.

IFPA Forum Europe, 2022

Need a tweet to help act on NCDs?

The NCD Alliance has put together ready-made tweets that can inspire you as starting point talking about investment into NCDs. Here is an example

TWEET ME

39 million lives could be saved between 2023-2030 if the world's Health Ministries INVEST 20% of their budgets to high-priority #NCD interventions. Let's save lives & money. Act now on NCDs.

Need more? Visit the *ActonOnNCDs.org*

For more social media training, check out the *IFPA Accelerator*.

Navigating the playbook

Involving patient associations and their members in decision-making

Globally, there is a need for patient involvement in policy development and decision-making. Quality care requires that people living with a disease are actively involved in all decision-making that impacts how they live with and manage their condition. This involvement will improve patient experiences and outcomes.

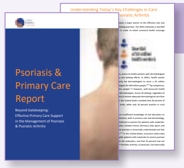
Why not do a patient survey?

A mental health and wellbeing survey with your national community of people living with psoriatic disease may generate a representative sample of people who face mental health challenges and consider their needs significantly unmet. This can be used to generate traditional (eg. print and radio) and digital media coverage, create a reason for writing to a politician or kick-start a social media campaign demanding change.

How to take action:

Motivate that patient organizations must be part of the policy-level decision-making process

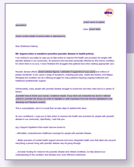
Psoriasis and primary care report



Recommendations for advancing the management of psoriasis in a primary care-centric model.

Resource

Letter to a politician or Ministry of Health with clear ask for (selectable) themes



A letter template on the Roadmap themes to adapt and use.

Tool

Advocate for greater investment in NCDs that includes psoriatic disease

2022 Global Week for Action on NCDs: Actions for Alliances

Visit the Act on NCDs website for resources from the NCD community to support local advocacy efforts.

Resource

Navigating the playbook

A playbook with tools for action
Thematic action areas
Mental health, stigma, and quality of life
Access to care through earlier diagnosis and better financing
Health workforce for better diagnosis and treatment
Involving patient associations and their members in decision-making
Digital transformation and telemedicine to improve care
Putting the playbook into action
Tools and resources

Digital transformation and telemedicine to improve care

The role of technology in health care including dermatology is expanding. Physicians and patients are increasingly using telemedicine to manage psoriatic disease. Opportunities exist to improve the equitable delivery of health care for people with psoriatic disease, but clearer frameworks are also needed to safeguard those users.

Start an alliance and put together a policy on telehealth

Share *principles for telehealth policy* with stakeholders for review and feedback. Develop a similar policy to address access to care issues with overburdened specialists while safeguarding patient data, rights, and privacy in your locality.

How to take action:

Ask for the integration of telehealth models in order to improve access to specialist care

Telemedicine for psoriatic disease report

A review of the opportunities and challenges, best practice examples and a call to action to inform and inspire your telehealth initiatives.

Resource


COVID-19 and Explosion of Virtual Visits

IFPA

December 2021

TELEMEDICINE
for Psoriatic Disease Care

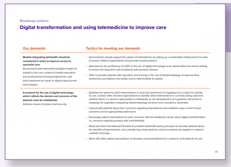
Establish a protocol for the use of digital technology which reflects the desires and concerns of the patients

Principles for telehealth policy

Six key principles informed by 35 patient and consumer advocacy organisations could act as a blueprint or template for your own national telehealth standards work.

Resource

Core telemedicine priority areas


Digital transformation and using telemedicine to improve care

Demands and tactics from the Roadmap for advocacy and engagement planning.

Resource

Putting the playbook into action

Here are examples on how you can use the resources and tools in this playbook.

Theme	Challenge	Audience	Tool	Learning resource
Mental health, stigma and quality of life	Eliminate the stigmatization of people with psoriatic disease	General public, family, friends	Social Media Toolkit - *link* Media story for pitching locally	Breaking the vicious cycle – Report - *link*
Access to care, earlier diagnosis and financing	Advocate for a multidisciplinary approach in caring for people living with psoriatic disease to support better managing the disease and detecting comorbidities	Educate policymakers, health payers, primary health care providers	IFPA's Resources for Universal Health Coverage Tools and resources - *link* Advocacy toolkit for UHC - *link* Letter to politician to Ministry of Health - *link*	Our vision for psoriatic disease and universal health coverage – Report - *link*
Health workforce for better diagnosis and treatment	Embed shared decision-making between providers and patients to guide treatment choices	GP's, family doctors, nurses, midwives, all front-line primary health care providers	WHO video – Let's talk about people-centred care - *link* Report - Psoriatic disease and primary care - *link* Meeting in a box for roundtable or one-on-one - *link*	Guide to [new] treatments approved by EMA for people living with psoriatic disease (e.g.) - *link*
Digital Transformation and telemedicine to improve care	Seek to improve access to care for people in places challenged by a lack of local expertise	Policymakers, health systems, specialist centres of excellence	Report – Telemedicine for psoriatic disease care - *link*	Best practice resource: National Psoriasis Foundation telehealth policy principles - *link*

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the playbook

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Thematic action areas

Tools and resources

Tools and resources archive

Steps from advocacy to action

Reach out

Tools and resources archive

Tools

IFPA Mental health and psoriatic disease toolkit - *link*

IFPA advocacy toolkit for Univeral Health Coverage - *link*

IFPA Social media toolkit on psoriatic disease and diabetes - *link*

Letter to a politician or Ministry of Health with clear ask for (selectable) themes - *link*

Media story for pitching locally - *link*

Medical appointment checklist - *link*

Meeting in a box for roundtable or one-on-one - *link*

Resources

Addressing NCDs: Psoriasis and its Co-morbidities - *link*

A practical guide to strategic advocacy planning - *link*

Checklist for your clinical journey - *link*

IFPA Forum Roadmap Europe - *link*

Factsheet on Universal Health Coverage - *link*

Healthier together – EU noncommunicable diseases initiative - *link*

The GPP Charter - *link*

Principles for telehealth policy - *link*

Promote a better understanding of the link between mental health and psoriatic disease - *link*

Real-world research study - *link*

White paper on Universal Health Coverage - *link*

WHO Resolution on psoriasis - *link*

WHO Global report on psoriasis - *link*

Working it out - *link*

Psoriasis and primary care report - *link*

Telemedicine for psoriatic disease report - *link*

2022 Global Week for Action on NCDs: Actions for Alliances - *link*

Videos

Awareness-raising video of the mental health impacts of psoriatic disease - *link*

Online Gaming: A resource kit for activation - *link*

What is people-centred care? - *link*

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Steps from advocacy to action

Reach out

Steps from advocacy to action

Over the past three years, several steps have been taken to guide IFPA member associations in Europe along the pathway from hosting a regional Forum event to producing an actionable *IFPA Forum Roadmap Europe* for establishing psoriatic disease as a health care priority, and for improving day-to-day experiences of people living with the disease.

2021

Forum preparation


Access to care (early diagnosis and finance for care)

IFPA Forum 2022 themes


IFPA

Speaking up for psoriatic disease in Europe

Briefing book: Speaking up for psoriatic disease in Europe

2022

Forum event

IFPA Forum Europe 2022


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

IFPA FORUM

Roadmap for patient associations to improve care for people with psoriatic disease

2023

Post-event


IFPA FORUM

IFPA Europe Action Playbook

IFPA Europe Action Playbook

2024

Beyond the Forum

Together, we are working towards psoriatic disease being recognized as a serious non-communicable disease in Europe.

Reach out

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Slottsbacken 8
111 30 Stockholm,
SWEDEN