IFPA FORUM
AFRICA 2026

A ROADMAP TO CARE

Improving psoriatic disease care across Africa

Local strength, united action:
A strategic plan to guide regional and national advocacy on psoriatic disease

Contents

Psoriatic disease in Africa

More than 3.5 million people are estimated to be living with psoriasis in Africa, but the disease remains widely unknown.[1] Under-resourced healthcare systems, plus limited awareness, barriers to adequate care, entrenched stigma, and significant gaps in research mean that many individuals go undiagnosed, untreated, and mistreated. For those affected, the impact reaches far beyond the skin, touching mental well-being, social relationships, and economic viability and stability for themselves, their families, and their communities.

About this Roadmap

In May 2026, stakeholders convened in Nairobi, Kenya, for the IFPA Forum Africa. People living with psoriatic disease – representing their country's patient support associations – experts in related matters, civil society, healthcare professionals, and private-sector partners came together to share and discuss achievements and challenges in order to identify further opportunities for collaboration. This Roadmap is an outcome document of the Forum, developed to guide national advocacy and local action toward achieving more equitable health rights for all through representation and participation. It sets out advocacy priorities and practical strategies to overcome the burden of the disease in resource-limited settings.

1. Global Psoriasis Atlas (GPA). 2026. https://www.globalpsoriasisatlas.org.

Ingvar Ágúst Ingvarsson,
President, IFPA

Foreword

Some moments stay with you, and the regional IFPA Forum held in Africa was one of them. The Forum marked a historic first – a dedicated continental dialogue about psoriatic disease grounded on African soil. That milestone alone speaks volumes. It is a declaration that the stories, challenges, and leadership of the African psoriatic disease community belong on the global stage. But beyond the symbolism, what stood out most was the people. The resilience, warmth, and creativity shown in the face of complex barriers were both humbling and inspiring. May each of you carry that strength home to your own communities.

The Forum's three themes – Research, Rights, and Representation – are not intangible ideals. They are the practical levers of change. We must build the local evidence base, secure access and dignity for every person, and ensure people with psoriatic disease have a seat at the table. This Roadmap distills the priorities discussed at the Forum into a framework that patient associations can use to strategically plan their advocacy initiatives and beyond.

Honoring the late Dr. Hosea Waweru, IFPA's former president, in his home country and in the presence of his family and the wider psoriatic disease community was a powerful reminder of the positive difference one person can make to so many lives. His legacy of advocacy, along with the commitment and support of those around him, showed us something important. It highlighted that when we are united in purpose, we have the strength to create real and lasting change.

The road ahead requires all of us. No single person, organization, or country can carry this alone. If we leave Nairobi with one shared conviction, let it be this: unity is our greatest strength, and change begins when we act together. Brighter days are possible; they can be built through persistence, partnership, and shared purpose.

Ingvar Ágúst Ingvarsson,
President, IFPA

IFPA Forum Africa:

One conversation, many voices

The IFPA Forum Africa created a space for shared learning, honest exchange, and collective problem solving, one conversation shaped by many voices. Its message was clear: for people living with psoriatic disease in Africa, the time has come to speak up and be heard. As Pierre Célestin Habiyaremye, President of PsorAfrica and founder of the Rwanda Psoriasis and Psoriatic Arthritis Organization, said in his opening remarks:

"By convening here in Nairobi, you're sending a powerful message that millions of people living with psoriatic disease are no longer at the margins of discussion. We are today at the center of discussion."

The agenda centered on real needs: addressing gaps in diagnosis and treatment, integrating psoriatic disease into broader non-communicable disease (NCD) strategies, strengthening its inclusion in national health policies, and improving care within under-resourced health systems. Discussions also focused on dermatology training for healthcare workers, reaching rural communities, and generating local prevalence data to strengthen political will. Examples shared showed that, even with limited resources, progress is possible.

Crucially, the Forum was designed to go beyond conversation. Participants worked toward practical solutions, including strengthening patient advocacy networks, sharing tools that work across contexts, and laying foundations for sustained regional collaboration. For patient associations, it offered a rare opportunity to learn from peers and experts, discuss potential advocacy efforts, and engage with medical professionals and policymakers through workshops. For many advocates new to IFPA, it was also a chance to be with others who share their lived experiences.

The three-day Forum wrapped up with real "wins" for mobilizing the advocacy agenda in Africa. For the first time, local psoriatic disease organizations held a joint dialogue with representatives from the Ministry of Health and the NCD space. Regional media attention was drawn to the event and to psoriatic disease, and local representatives elected the PsorAfrica board members who will lead united patient association efforts across the continent.

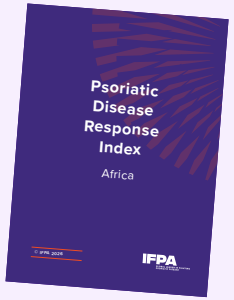
Supporting documents

Briefing Book →

A fact-based resource document that provides advocates with the evidence and arguments to frame the relevant issues in psoriatic disease in Africa.

Theme Briefs →

Three one-page theme briefs that can be used as a conversation starter or "leave-behind" when meeting with stakeholders.



Psoriatic Disease Response Index – Africa →

The report analyzes how four countries – Ghana, Kenya, Rwanda, and South Africa – are implementing the recommendations laid out in the World Health Organization (WHO) Global Report on Psoriasis.

The Action Playbook →

The playbook offers inspiration, resources, and tools to motivate patient associations to develop localized advocacy plans and activities aligned with the strategic goals of this Roadmap.

A strategic roadmap

Each IFPA Forum, held annually since 2022, has developed a strategic roadmap to guide follow-on and follow-up processes. Similarly, this Roadmap is intended as a practical framework to support advocacy efforts in the years ahead, helping IFPA members and patient advocates focus their plans on actions that can improve the lives of people living with psoriatic disease across Africa.

Structured around three themes – Research, Rights, and Representation – the Roadmap reflects the areas where advocates on the continent can collectively drive the greatest change. These themes were determined through discussion and consensus among IFPA, PsorAfrica, and trusted experts who understand the region's challenges, the unmet needs of people living with psoriatic disease, and the crucial role advocacy plays in igniting change. They provided an anchor for Forum discussions and a scaffold for orienting actions after the Forum.

Living with psoriatic disease is challenging everywhere, but no country or region is exactly alike. Across Africa, people navigate healthcare systems shaped by distinct social, cultural, economic, and political realities. In a region where psoriatic disease was long overlooked or misunderstood, the opportunities to build and strengthen advocacy are significant. At the same time, in many countries, this work is only beginning.

This Roadmap recognizes that different patient associations are at different stages of development and that advocacy priorities need to be adapted to local realities. The priorities, commitments, and feasible solutions set out here are intended to support localization, so that patient associations and partners can translate them into strategies that fit their own national context and capacity.

Research

Data on every aspect of psoriatic disease in African populations to support informed, evidence-based decisions on improving the lives of those affected.

Local data and evidence →

Rights

Access, equity, and quality care – ensuring appropriate medicine availability, affordability, and quality care for all with psoriatic disease.

Access to care →

Representation

People living with psoriatic disease must be included and participate in decisions about research, policy, and leadership on NCDs.

Testimonies from lived experience →

Roadmap overview →
Access a complete overview of the Roadmap, including the objectives, feasible actions, and success measures.

RESEARCH

Local data and evidence

Reliable data on the prevalence, impact, and treatment outcomes of psoriatic disease in Africa remain scarce or non-existent. Without this evidence base, policymakers lack the information needed to prioritize the condition, allocate resources, or make the case for improved access to care.

How do we succeed?

Keep your network broad, as many research opportunities arise through collaborations across geographies.

Feasible actions →

Advocacy priority

Data on every aspect of psoriatic disease in African populations to support informed, evidence-based decisions on improving the lives of those affected.

Advocacy commitment

Ensure that psoriatic disease is recognized, counted, and understood across Africa. This means knowing how many people are affected and their experience, establishing registries that capture the true burden of disease, and ensuring people from Africa are included in clinical trials so that treatments developed reflect their needs.

What success will look like

Reliable data on prevalence, the impact on individuals and healthcare systems, and the effects of treatment on the outcomes of psoriatic disease are used to successfully influence policy.

Partnering for success

Mentioned at the Forum was a partnership between the Psoriasis Association Kenya (PAK) and the Danish Psoriasis Association (Psoriasisforeningen), which is supporting a prevalence study in Kenya. **In Ghana, the patient association is supporting student-led prevalence and research work**. Other types of research-related partners include universities, research organizations or networks, patient groups, health ministries, international agencies such as the WHO, research funders, and private industry.

FORUM SPEAKER

Patient advocacy must be grounded in evidence and translated into policy.

Advocates need strong prevalence and burden data, patient inclusion from the start of policy-making, alignment with national medicines lists and health policy processes, and learning from successful advocacy models in other diseases and countries.

Insight shared by **Dr. Edwin Kojo Ogara,** WHO Kenya Country Office

RESEARCH **LOCAL DATA AND EVIDENCE**

Feasible advocacy actions

The case for data is not abstract. It is the difference between being on a government's agenda and being invisible to it. Decision-makers need the evidence to determine how to allocate resources based on the number of people affected, the cost, and the long-term impact.

01

Develop prevalence studies

Healthcare decision-makers need prevalence data to form a well-defined understanding of the disease burden within the population. Prevalence studies provide estimates of how many people are affected within the general population. Studies also often document the number of new cases or incidence, which helps with healthcare provision planning.

Road to integration
Identify potential collaborators and funding opportunities. Reach out to international partners, including other IFPA member associations, that may have experience designing or supporting prevalence studies.

Practical considerations
Use the published findings in advocacy with policymakers to drive recognition and action.

Success metric
New prevalence data published across Africa.

"How do we make our **business case** to convince pharmaceutical companies that Africa can be a market to make money? We need to have a number for them on how many people are affected by psoriatic disease."

Pierre Célestin Habiyaremye,
PsorAfrica, Rwanda

RESEARCH **LOCAL DATA AND EVIDENCE**

02

Establish, standardize, and scale local registries

Registries capture "real-world data" about people living with a disease. Data captured may include prevalence, demographic, and clinical information, which can be fed into institutional and government data systems. African countries lack centralized or standardized patient registries for psoriatic disease, leading to fragmented data that obscure the actual extent of the disease burden.

Road to integration
Work with professional researchers, healthcare centers, and ministries to pilot the development of registries. Begin by mapping the data already available in your country, establish whether it is suitable to use, then work with partners to identify gaps and agree on the study measures. Build capacity to maintain and analyze registries.

Practical considerations
Creating local registries with standardized data-collection methods enables pooling across sites, making psoriatic disease more visible to policymakers and supporting funding and policy change.

To facilitate analysis across centers and regions, establish data-sharing agreements to create regional databases.

Success metric
A registry established in every sub-region of Africa.

03

Support clinical trial research

Clinical trials in Africa face barriers, including low awareness, limited infrastructure, language and cultural challenges, and low patient involvement in trial design. Patient associations can assist by filling implementation gaps, such as expanding the inclusion of individuals in remote areas in trials. This may include ensuring that patient advocates are enrolled early in trial design to build trust and improve recruitment, or addressing language and cultural barriers to ensure inclusive participation.

Road to integration
Promote the development of multicountry collaborations linking hospitals and research institutions. Involve patient advocates. Secure resources, including funding for infrastructure, staff support, and publications. Advocate for regulatory frameworks that accommodate local contexts and multilingual materials, increasing trial accessibility and diversity.

Practical considerations
Research centers are pivotal to developing clinical research, and linking these clinical centers through networks can facilitate trial implementation. **IFPA's Breaking Barriers initiative** is an online resource for advocates and healthcare professionals who want to learn more about clinical trials.

Use the QR code to learn more about IFPA Breaking Barriers →

Success metric
Number of clinical trials in each sub-region.

RESEARCH **LOCAL DATA AND EVIDENCE**

04

Conduct surveys investigating the unmet needs of people living with psoriatic disease, their caregivers, and healthcare providers

Surveys capturing the unmet needs of people living with psoriatic disease help quantify patient experiences as well as those of their caregivers and healthcare providers. These surveys are used to inform policy by highlighting treatment and care gaps, which helps to determine resource allocation and targeted interventions.

Road to integration
Partner with regional patient groups and academic institutions to design and deploy standardized unmet needs surveys. Use digital tools to reach wider populations. Analyze and disseminate results widely. Incorporate findings into advocacy strategies and health planning.

Practical considerations
Known challenges with surveys include low response rates to questionnaires or a small pool of potential respondents, which can make it harder to trust the results or apply them to the broader population. One way to overcome these obstacles is to join forces with other organizations, such as patient associations working in NCDs or skin diseases, as was done in Latin America with the COLLAPIEL (Coalición Latinoamericana de Pacientes de la Piel) multicountry unmet needs survey.

Success metric
A regional survey uncovering the burden of people living with psoriatic disease.

"Our global health narrative on psoriasis needs to change. We need to do more to elevate the African lived reality on the ground."

Melini Moses, South African Psoriasis Association

RIGHTS

Access to care

Multiple, compounding barriers shape access to care for people with psoriatic disease. These include the availability of healthcare professionals equipped to diagnose and treat the disease, access to appropriate medications, and the affordability of treatment.

How do we succeed?

Building relationships with the right partners can significantly strengthen impact.

Feasible actions →

Advocacy priority

Quality and equitable access to appropriate medicines that are available and affordable to all people living with psoriatic disease is central to the right to health and a universal priority.

Advocacy commitment

Ensure that people living with psoriatic disease can access appropriate treatment, in an accessible place and timely manner, regardless of where they live. This means securing medicines on national essential medicines lists, building the workforce needed to diagnose and manage the condition, and using digital tools when possible to extend recognition, care, and support beyond urban centers. While data and connectivity can be problematic in many parts of Africa, cellphone use is widespread, even in rural areas.

What success will look like

Access to essential medicines for psoriatic disease within universal health coverage, a knowledgeable and trained healthcare workforce able to recognize and diagnose psoriatic disease, and people living with psoriatic disease with access to these services, even in remote regions.

Partnering for success

Natural allies may include dermatologists, rheumatologists, medical schools, ministries of health, pharmaceutical companies, and community health networks. International organizations such as the WHO and IFPA can add credibility and provide tools, while other patient associations working on access issues can offer solidarity, shared learning, and a stronger collective voice.

FORUM SPEAKER

Progress on access is possible through persistent, stepwise advocacy.

*"I need to say that **we've come a long way in Egypt, which I'm very proud of.** At the very beginning, our access to treatment was very limited, but we're increasingly trying to get the government to subsidize more expensive therapies."*

Prof. Mahira El Sayed,
Ain Shams University, Egypt

RIGHTS **ACCESS TO CARE**

Feasible advocacy actions

The barriers to access are real, but so are the potential opportunities. From Kenya's upcoming review of its Essential Medicines List to Egypt's incremental progress on subsidized biologics, there are windows of opportunity and workable solutions across the region that patient associations can learn from and, with the right partners, help scale.

01

Advocate for availability and access to affordable psoriatic disease medicines

National medicines lists guide procurement, funding, and prescribing decisions. Advocacy can push governments to align these lists with WHO recommendations or add treatments relevant to local needs. These lists are periodically reviewed, and communities have a recognized role in shaping them.

Road to integration
Establish a coordinated advocacy plan that includes gathering and presenting local evidence, engaging key stakeholders early, and maintaining ongoing communication with national committees to ensure timely inclusion of psoriatic disease treatments in national essential medicines lists.

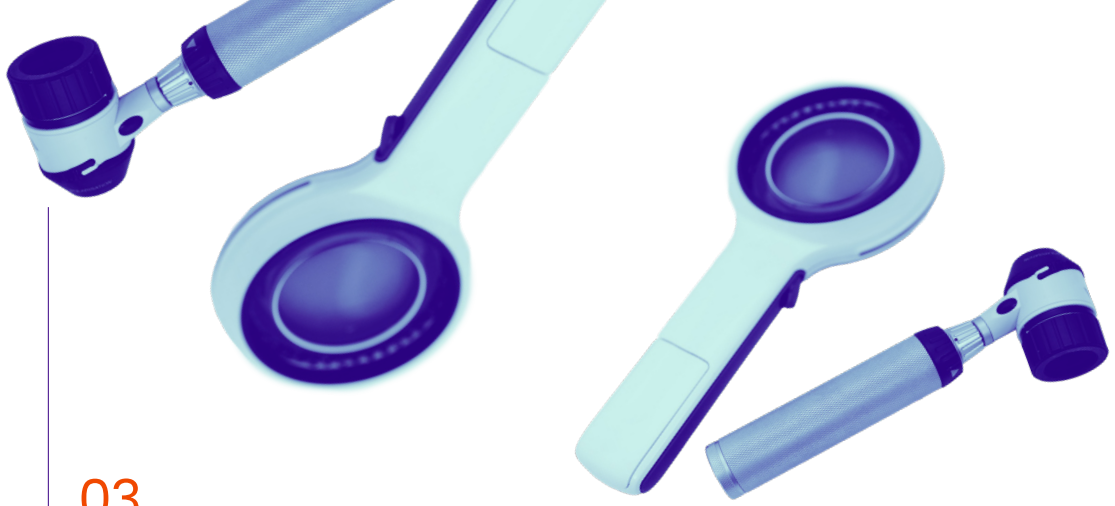
Practical considerations
The WHO provides normative guidance that can be adapted locally, including the WHO Essential Medicines List, which is an evidence-based reference for developing national and institutional medicines lists.

Success metric
More countries formally adding WHO-recommended medicines to their essential lists.

"Have you ever looked at yourself in the mirror and asked which is more important, the **cost of medicine** or the cost to live? Many times, I've stopped going to see the doctor because of cost."

Tina Ochsner, Psoriasis Association of Kenya

RIGHTS **ACCESS TO CARE**



02

Provide training and/or education materials for frontline workers

Frontline staff, such as nurses and community healthcare workers, play key roles in community healthcare, including early diagnosis and holistic patient support. Relevant training is urgently needed for these healthcare workers to address the obstacles related to limited resources. When patient associations are suitably equipped, they can support training initiatives by offering training, producing and distributing training materials, or recommending courses developed by international organizations such as the WHO.

Road to integration
Collaborate with partners to adapt and expand accessible training resources tailored to local frontline healthcare needs. Train general practitioners and nurses to recognize common dermatologic problems, providing simple techniques with diagnostic algorithms, and educating them on differentiating psoriatic disease from eczema or fungal infection, initial management, and when to refer patients to specialists.

Practical considerations
Many of the resources needed to support education and training already exist, so organizations do not need to start from scratch. IFPA also offers educational and training materials, including the WHO Academy's certified psoriasis course, a course on psoriasis created for all healthcare professionals.

Success metric
The number of frontline healthcare workers trained.

03

Extend dermatology training within general medical education

Equipping general practitioners with foundational dermatology knowledge, reinforced through practical exposure, supports earlier identification, appropriate first-line management, and timely referral. Embedding psoriatic disease within general medical education helps ensure that all doctors can recognize common presentations, understand comorbidities, and respond without reinforcing stigma or misconceptions.

Road to integration
Engage with medical schools, teaching hospitals, dermatology departments, and professional councils to review existing curricula and identify entry points for psoriatic disease content. Advocate for lectures, case-based learning, and supervised clinical rotations that expose students to dermatology in primary care, referral clinics, and community settings.

Practical considerations
Curriculum change can be slow, so begin with practical additions that are easier to adopt, such as guest lectures, short modules, image-based diagnostic tools, or elective placements. Patient associations can contribute lived-experience perspectives and help ensure training addresses stigma, referral pathways, and the realities of care in resource-limited settings.

Success metric
Dermatology theory and practical learning modules included within undergraduate medical education.

RIGHTS **ACCESS TO CARE**

04

Support graduate dermatology programs and facilitate continued education

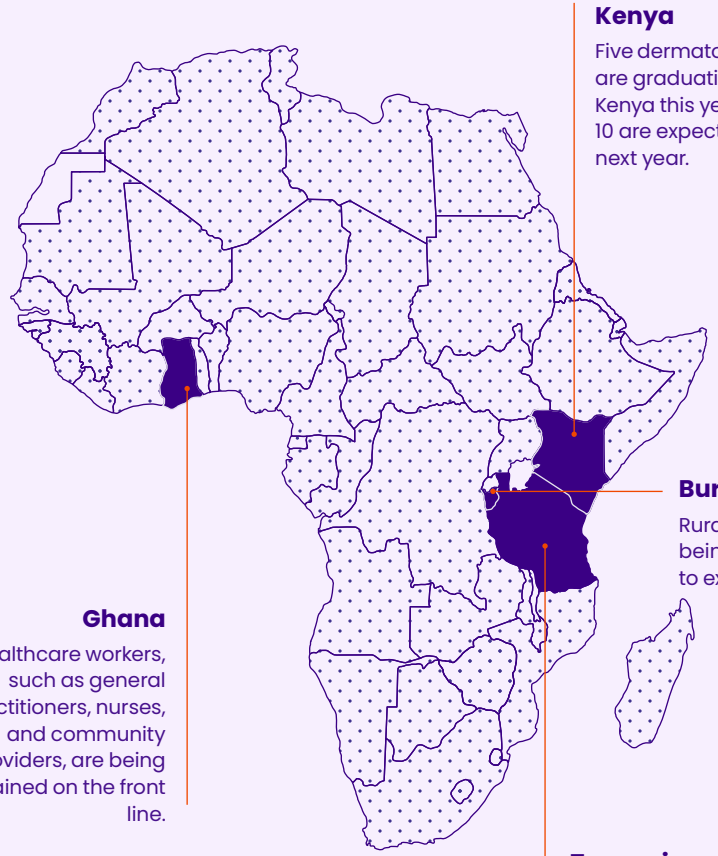
Addressing the serious shortage of dermatologists and rheumatologists requires dedicated training pathways. Diploma and Masters programs in clinical dermatology exist in some African countries and are open to regional candidates. Continuing professional development ensures practicing clinicians remain updated on evolving treatments and clinical standards in psoriatic disease care.

Road to integration
Engage with local medical schools and teaching hospitals to support graduate programs. Integrate psoriatic disease into training. Build capacity within the healthcare workforce.

Practical considerations
Consider avenues of support, such as grant funding, to expand access for students across the region.

Success metric
A baseline with growth targets set for the number of graduates enrolled in postgraduate dermatology programs, and healthcare professionals being upskilled through webinars and courses.

Education and training to improve healthcare workers' knowledge of dermatology in Africa



Kenya
Five dermatologists are graduating in Kenya this year and 10 are expected next year.

Burundi
Rural clinics are being established to extend reach.

Ghana
Healthcare workers, such as general practitioners, nurses, and community providers, are being trained on the front line.

Tanzania
Graduate training is available for dermatologists at the Regional Dermatology Training Center in Moshi.

RIGHTS | **ACCESS TO CARE**

05

Encourage the use of telehealth and digital tools to extend equitable care and support

Dermatology is largely a visual discipline that lends itself to sharing images digitally. Teledermatology enables clinicians at remote clinics to consult with specialists by securely sharing photos via their electronic devices. Digital tools are increasingly used across the continent, enabling faster, more accurate diagnoses and reducing the need for travel for people living with the disease. For example, at the Forum, we heard that in **western Kenya, teledermatology connects primary care physicians in rural health facilities with a dermatologist** who reviews images remotely, provides a diagnosis, recommends treatment, and advises referrals if needed.

Road to integration
Investigate whether teledermatology platforms have been used to connect remote clinics with urban specialists in your region. Is it possible to draw on these new patient-centered approaches to enable improved access to care in your country or region?

Practical considerations
Simple platforms like WhatsApp or Zoom can be used for educational webinars, helping people living with the disease connect with others for support. Digital media enhances low-cost relationships and connections and can bring care closer to people living with psoriatic disease. Moreover, it can be an effective tool for peer support.

Success metric
A case study on the scaled-up use of mobile apps and digital platforms across countries and regions to support care.

06

Highlight reproductive health support for women living with psoriatic disease

Achieving equitable care for all people living with psoriatic disease in Africa requires specific attention to women across their reproductive lives. Treatment choices carry implications for conception, pregnancy outcomes, and maternal health, making multidisciplinary planning essential. Women frequently forgo having children due to their disease, often on the basis of incomplete information. Reliable, culturally appropriate guidance supported by specialist input can help women make informed decisions and plan pregnancies with the lowest possible risk to mother and child.

Road to integration
Provide women living with psoriatic disease and their healthcare providers with trusted information to help them prepare for pregnancy and plan their families. Investigate what reproductive health services and multidisciplinary care pathways currently exist in your country or region for women with chronic diseases that women can access.

Practical considerations
Printed guidance materials, family planning consultations and antenatal visits, community health workers, patient support groups, and WhatsApp-based peer networks offer practical entry points where women with psoriatic disease can be educated, empowered, and supported with reproductive health decisions. Support must extend to the full reproductive health of women, beyond pregnancy and planning for conception. Areas where women need guidance include contraception, medication safety, breastfeeding, and postpartum disease management.

Success metric
The number of women of childbearing age with psoriatic disease adequately informed about their family planning choices and available support.

RIGHTS **ACCESS TO CARE**

07

Improve healthcare provider awareness of the disease to reduce stigma

Stigma can make doctors and nurses less willing to care for people with psoriatic disease, often due to unfounded fears of contagion or discomfort that leads them to distance themselves. Patients who anticipate or experience stigma may also avoid seeking help, undermining their treatment and care. Educating healthcare providers about psoriatic disease, stigma, its psychological impact, and its role as a barrier to equitable care is essential to ensure people receive the care they need.

Road to integration
Low-cost, simple visual materials, such as brochures, distributed to healthcare providers and via patient support channels can convey key messages around disease awareness, myths, stigma, and equitable care. Find out whether there are existing continuing professional development courses that can include information on this topic or could potentially highlight this issue.

Practical considerations
Patient testimonials and lived-experience narratives are particularly effective at shifting attitudes among clinical staff.

Success metric
Healthcare providers surveyed have higher knowledge scores and lower stigmatizing attitudes from baseline.

"Our mission is to create awareness, advocate for better treatment, and support families affected by psoriatic disease. Behind every statistic are real people: children who struggle to fit in at school, adults who face **stigma and discrimination** in the workplace, and families bearing the emotional and financial burden of this condition."

Ambassador James Waweru, Kenya's Deputy Permanent Representative to the United Nations in Geneva

REPRESENTATION

Testimonies from lived experience

Testimonies coming from lived experiences are often underrepresented in health system design and policy decisions, especially those of young people, who are often marginalized or not included at all, limiting the impact of advocacy and the relevance of services to those living with psoriatic disease.

Advocacy priority

People living with psoriatic disease must be included and participate in decisions about research, policy, and leadership on NCDs.

Advocacy commitment

Ensure that patient associations are formally recognized and actively involved in national NCD and universal health coverage (UHC) policy processes to ensure equitable, person-centered, and quality care.

What success will look like

Psoriatic disease is known and recognized as an NCD within communities, and people living with the disease actively and meaningfully participate in policy processes related to psoriatic disease and NCDs.

How do we succeed?

Building patient representation takes relentless effort, but many of the foundational tools are within reach.

Feasible actions →

Partnering for success

Partnerships can help unlock necessary resources for effective advocacy. Key stakeholders can include patient groups, collaborating with HIV/TB programs that already have strong grassroots networks, **aligning with the NCD Alliance to advocate for chronic care integration as the patient association in Ghana has done**, or partnering with disability rights organizations to promote inclusion and enhance reach, credibility, and policy influence through joint campaigns and shared resources.

FORUM SPEAKER

"Piggyback" on aligned structures and present psoriatic disease as a measurable public health and financing issue.

"To make the case for psoriasis, we need to position it within existing NCD structures, generate the data, and show the cost and quality-of-life impact clearly enough for decision-makers to act."

Dr. Stephen Mutiso,
NCD division, Ministry of Health, Kenya

REPRESENTATION **TESTIMONIES FROM LIVED EXPERIENCE**

Feasible advocacy actions

The Forum made clear that the demand for patient representation is not symbolic but structural, and that youth engagement must be activated. Awareness of the disease can open doors to rooms where people make decisions about health and NCDs.

01

Conduct awareness campaigns

Stigma remains one of the most significant barriers faced by people living with psoriatic disease in Africa. Across the Forum, advocates described experiences of being seen as contagious or cursed, whether in school, workplace, or healthcare settings. Awareness campaigns that center on the African lived experience and directly challenge misconceptions can shift public understanding and reduce the isolation that many people feel.

Road to integration
Identify the most common misconceptions about psoriatic disease in your community and develop simple, culturally relevant messages to address them. Start with the channels your community already uses. Connect with media professionals and look for opportunities to place the stories of those with lived experiences in local outlets.

Practical considerations
Low-cost, high-reach tools, such as WhatsApp groups, social media campaigns, community events or radio, and media partnerships, have already shown impact. **In South Africa, patient advocates have used media campaigns and a 150-member WhatsApp support community** to raise visibility and connect people. There is also a wide range of examples from patient association awareness activities, for example World Psoriasis Day initiatives, to take inspiration from.

Success metric
A record of media exposure and public attention on psoriatic disease.

"The best way of actually working with young people is to give the decision-making and **real power to young people**, to share that power, to give up some of your power to young people, to work together to get the best outcomes, the best program, and the best information to young people."

Guuled Mohamed,
UNICEF Sweden

REPRESENTATION | **TESTIMONIES FROM LIVED EXPERIENCE**

02

Strengthen and support local patient associations

The Forum repeatedly demonstrated that when patient associations are well established, people living with psoriatic disease are better supported, better heard, and better represented. In Africa, though, many associations are small, under-resourced, or only recently formed. Building membership, increasing visibility, and creating a welcoming culture, particularly for those newly diagnosed, strengthen the association's credibility and reach.

Road to integration
Assess what your association currently offers members and identify gaps in support or communication. Consider developing peer-support structures, patient resources, or regular events that give members a reason to stay engaged.

Practical considerations
Reach out to IFPA for tools, guidance, and connections to associations in similar contexts. Where no association yet exists, connect with interested individuals through clinical networks or online communities and explore the steps to establish one with IFPA and PsorAfrica. **IFPA's Accelerator Program has already helped new organizations in countries such as the Gambia and Nigeria take their first steps toward formal membership.**

Success metric
At least two more patient associations for each sub-region of Africa by the region's next Forum.

03

Activate youth advocacy

Young people want to learn and be involved; however, they face barriers, including a lack of clear pathways, communication that does not meet them where they are, and a failure to follow through after initial engagement. The Forum's dedicated session on youth participation highlighted a recurring problem: young people are invited in as token representatives rather than empowered as leaders. Reversing this requires genuinely listening to their needs, being open to other ways of doing things, and being willing to share power.

Road to integration
Start by asking young people in your community what they need and what would make them want to be involved; avoid assuming. Create defined roles with real responsibilities. Use platforms young people already use, and communicate in ways that are accessible and relevant.

Practical considerations
Mentorship structures that connect new young advocates with more experienced individuals can create a snowball effect, with youth champions training future champions.

Success metric
Number of patient associations with youth structures, and number of NCD and health forums attended by young leaders.

REPRESENTATION **TESTIMONIES FROM LIVED EXPERIENCE**

04

Establish partnerships and dialogue platforms

The most effective advocacy draws on coalitions that bring together patient groups, medical societies, civil society organizations, and policymakers around a shared agenda. The recent signing of a **mutual agreement on a regional collaboration to improve patient care across Latin America**, following talks among stakeholders at the IFPA Forum Americas 2025 in Bogotá, underlines the power of creating platforms for dialogue and the role of patient associations in facilitating these processes.

Road to integration
Map the policy and advocacy landscape in your country. Identify which NCD forums, universal healthcare committees, or health ministry working groups are relevant, and who already has a seat at those tables. Identify one or two coalition partners whose agendas overlap with yours, and initiate a conversation about shared goals. Develop a clear advocacy ask. One suggestion is to request that psoriatic disease be included in your country's national strategy for the prevention and control of NCDs.

Practical considerations
Connect with PsorAfrica and IFPA to understand regional advocacy priorities and align your national efforts with the broader continental voice. IFPA and other international networks can provide guidance, templates, and connections to help associations build their capacity.

Success metric
A mutually agreed partnership or coalition with a shared agenda, formal mechanisms for patient engagement in policy development, or a record of patient groups represented within NCD and UHC policy processes.

05

Attend and actively participate in policy discussions around NCDs and health

People living with psoriatic disease or other NCDs are too often absent from the forums where decisions affecting their care are made. Building a consistent presence within national, regional, and global health platforms ensures that lived experience informs policy and that patient voices carry weight alongside clinical and technical expertise. Representation is most effective when actively pursued over time.

Road to integration
Advocacy participation generally progresses from national to regional to global, each level building on the credibility and relationships established at the one below. Some patient groups working at national level progress in their advocacy journey by engaging with national NCD alliances, then advance their work by engaging with the local ministry of health through ministry consultations. Other regional or global organizations may seek observer status at WHO regional offices and, eventually, participate in international gatherings such as UN High-Level Meetings or World Health Assembly and related side events.

Practical considerations
Reflect on what makes representation meaningful rather than tokenistic. Join existing coalitions, bring evidence-based policy briefs, secure formal participation status, and maintain a presence across policy cycles.

Success metric
A record of the number of patient groups represented within NCD and UHC policy processes.

From Forum to action

Monitoring, evaluation, and accountability

Knowing what you are trying to achieve and how you will know when you have achieved it is not an administrative detail to catch up on later. It must be written down at the outset when formulating a credible, sustainable advocacy plan. Setting clear goals, defining measurable indicators relevant to your community's needs with realistic timeframes, and establishing accountability mechanisms from the outset are important because they provide direction for your work.

Building monitoring and evaluation into your advocacy plan from day one can transform ambition into evidence, and evidence into change. As you put together your plan, keep in mind the words of one of history's influential management thinkers:

"What gets measured gets done, what gets measured and fed back gets done well, what gets rewarded gets repeated."

The advocacy journey from idea to end goal can be long; clear, manageable milestones make it more accessible and provide positive reinforcement. Simple, consistent data collection, whether through tracking participation at events, media reach, or identifying newly diagnosed individuals, can generate the evidence needed to demonstrate impact and keep the momentum going. Reliable record-keeping is also fundamental to keep partners aligned and build the trust of international partners such as IFPA, policymakers, and funders who need to see that progress is being tracked and reported.

Patient associations have a role not only in tracking their own progress, but also in holding healthcare systems and policymakers to the commitments they make. Formal feedback mechanisms, such as representation on NCD committees or regular reporting to health ministries, create the structures for accountability and follow-through.

Hellen Wangui,
Psoriasis Association of Kenya

Each journey begins with a single step

This Roadmap is intended to support action. The priorities set out here are ambitious, but they are achievable when adapted to local realities and pursued with persistence. You only have to look at the remarkable achievements of other IFPA members and regions to know that the task ahead is possible.

Across the continent, advocates are starting from different places, but no one is starting alone. The Forum showed that there is strength in shared experience and power in coordinated action. United in action with a clear purpose, you will find the local strength you need.

Change rarely happens all at once. It happens through sustained effort, strategic collaboration, and the confidence to ask for what people living with psoriatic disease need and deserve. For advocates, the next step is to translate this shared agenda into practical plans. That may mean identifying one policy window, building one new partnership, collecting one new piece of evidence, or creating one stronger platform for patient voices.

Use this Roadmap as a guide, adapt it to your context, and keep building the movement for better care, better evidence, and stronger representation across Africa. There is no doubt that with your efforts, there are better days ahead for people living with psoriatic disease within our communities.

Let's take the next steps together!

Ambassador
James Waweru

Ready to develop your local advocacy plan?

Access the Action Playbook for further inspiration. The playbook also includes resources and tools, including the Strategic Advocacy Planning Toolkit, which provides guidance on identifying stakeholders who can provide input and support.

Read the Playbook →

Contacts

PsorAfrica

PsorAfrica champions dignity, access to care, and inclusion for people living with psoriatic disease in Africa, moving from silence and stigma toward visibility and access to treatment.

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IFPA

Founded in 1971, IFPA is the International Federation of Psoriasis Associations. We are the psoriatic disease community. Our members represent over 100 million people living with psoriatic disease. Together, we advocate for a future where all people living with psoriatic disease enjoy good health and well-being, free from stigma and preventable disability and comorbidities.

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