



International Alliance of
Dermatology Patient
Organizations

[GLOBALSKIN.ORG](http://globalskin.org)

GlobalSkin-Europe Community Engagement Plan 2022-2024



Introduction

The International Alliance of Dermatology Patient Organizations (also known as GlobalSkin), has been a driving force in uniting the world's patient organizations advocating for people living with dermatological conditions. GlobalSkin is working with 200+ patient association members — located in 65 countries representing more than 54 disease areas and growing.

The GlobalSkin-Europe Community was formed in 2021, comprised of nearly 90 patient organizations across 28 countries and representing 21 disease areas. GlobalSkin-Europe is a complex yet empowered network of advocates who are passionate to work together as a united voice.

Dermatology disease has been described as one of the most common human illnesses (1). There is clear evidence of the associated socioeconomic impact of the global burden of skin disease (2). However, it is overshadowed by other disease areas and not on the agenda of many of the leading policymakers at a European level. This European Community has come together under the guidance of GlobalSkin to move the discussion firmly to the center of health policy in Europe. The Community Engagement Plan is built on the strategic pillars of Joint Action and Community Strengthening and will draw on the foundation building blocks of action, build, and collaboration. The plan was built respecting the evidence and understanding gained for the GlobalSkin-Europe Landscape Analysis, undertaken in 2020, in collaboration with GlobalSkin's European Members.

To develop the community further, it is essential that while each member works on their unique challenges, they see and embrace the power of a united patient voice. Disease-specific conditions have a significant impact on the individual patient community. However, drivers of policy decisions in an individual disease community are not considered a large enough population to impact decisions. A united GlobalSkin-Europe Community will create an impactful population size, speak with a louder and more powerful voice and amplify the challenges experienced by many people living with skin conditions.

There are several tactics described below to achieve the overarching goal of the community engagement plan. Success is built around leveraging the value of The Global Research on the Impact of Dermatological Diseases (GRIDD) project. There is an agile approach to building in small steps towards reaching the overarching goal described below. The design has been created to allow for scaling depending on the resources available to the GlobalSkin-Europe team. The GlobalSkin-Europe Community will create a more significant impact with a unified voice. The plan is designed to drive forward the common goal to put dermatology top of the health policy discussion in Europe.



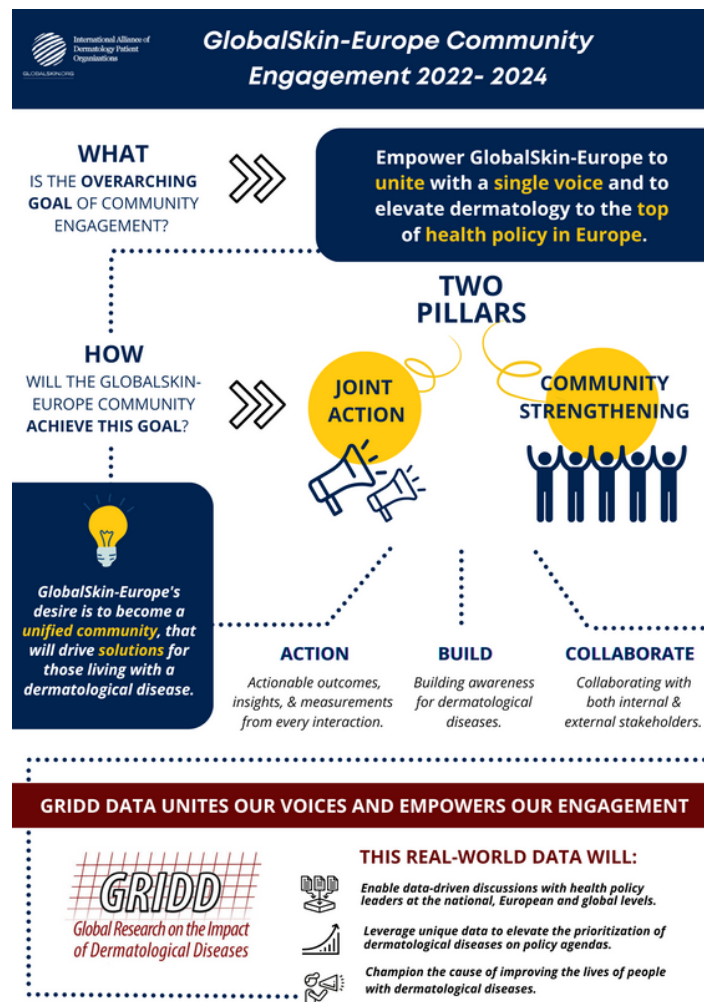
The overarching goal of the Community Engagement Plan:

Empower GlobalSkin-Europe to unite with a single voice and take a place at the top of health policy in Europe.

High-level overview

GlobalSkin-Europe Community Engagement Plan 2022- 2024 creates the opportunity to move forward with a clear focus and in a structured manner with the overarching goal to **“Empower GlobalSkin-Europe to unite with a single voice and take a place at the top table of health policy in Europe.”**

In order to deliver upon this goal, a simple process has been devised that can work at all levels of engagement by community members. The plan is designed to assist and use the two pillars of Joint Action and Community Strengthening. Each action should address and support the pillars by use of the three foundation building blocks of Action, Build, and Collaborate.



Tactics



The success of the Community Engagement Plan relies on delivering several tactics which complement the two pillars of Joint Action and Community Strengthening. Each tactic is iterative with a year-on-year expansion. The tactics presented are designed to create continued growth and success. They are flexible in timing and scale; the thinking was to reach the yearly outcomes and not limit the success depending on the resources available. Our plan is to increase internal community growth and external partner advancement by having more positive interactions at all interaction points. The outlined tactics focus on practical initiatives to realize our members' goals and are broken down into quarter deliverables over a three-year period. To avoid capacity issues with members, in-person or online events are limited to two at most during a quarter.

Defining the tactics:



Awareness Campaign

GlobalSkin-Europe will work towards the development of an awareness campaign, in conjunction with the Global Dermatology Coalition, which will include the results of discussions with different partners on the timing and concept of the European Skin Disease Awareness campaign. The launch is planned along with the designation of content and media awareness in 2023. 2024 will see the continued growth and development of the campaign. This awareness campaign is designed to take advantage of the GRIDD data and a key driver of the overarching goal of the community engagement plan: Empower GlobalSkin-Europe to unite with a single voice and take a place at the top of health policy in Europe.

Patient Derived Data

The Global Research on the Impact of Dermatological Diseases (GRIDD) project is the first comprehensive patient-led research on the impact of dermatological conditions in patients who live with these conditions. This project provides a unique opportunity to derive dermatology impact data directly from patients who suffer from a large spectrum of diseases. This impact data is vital to the success of placing dermatological disease at the top of health policy in Europe.

GRIDD data unites our voices and empowers our engagement. GRIDD will actively leverage the real-world data acquired and create the opportunity for evidence-based discussion with policy and health system leadership at the national, European Union (EU), and global levels. This research will create the opportunity to present unique data on the impact of dermatological disease on patients and help champion the cause of improving the lives of people with dermatological diseases.

A goal of the community is to insert the data from GRIDD into all discussions. GlobalSkin is committed to developing the capacity-building tools necessary for community members to initiate and create these impactful conversations. This rich set of data can drive discussion for Dermatology Patient Organizations as thought leaders in the field of patient-led evidence-based research.



E-learning sessions

The result of the global pandemic has seen an increase in the opportunity for e-learning resources. The community engagement will design an e-learning plan in 2022 to be implemented in 2023 and beyond. The sessions are designed to allow experts in various fields to share and develop great capabilities among the entire GlobalSkin-Europe Community. Example sessions would include members from different stakeholder groups speaking on topics like medical access, funding opportunities, digital health records, dermatological disease research topics areas, the GRIDD value proposition, etc.

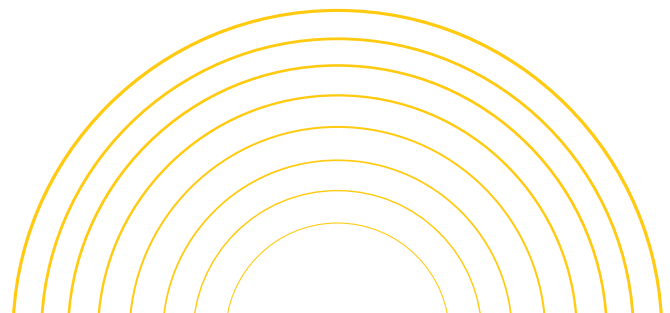
Annual community meeting

As a result of the pandemic, it has not been possible to have the much-desired face-to-face meetings over the last couple of years. If health measures allow, in-person Community events could return in 2022, which would be a great opportunity to connect, learn from each other and have discussions about the future of advocacy around dermatology diseases in Europe and globally.

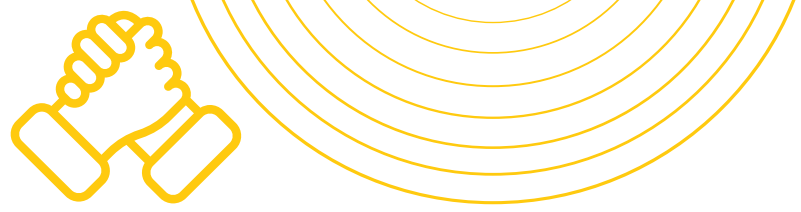


Europe policy discussion

GlobalSkin-Europe is committed to delivering on the overarching aim of the community engagement plan to **Empower GlobalSkin-Europe to unite with a single voice and take a place at the top of health policy in Europe.** To that end, a number of touchpoints are planned to connect with policy and central figures in European Health Policy. The initial contact is in engagement with the EU Health Policy Platform. Through connection, discussion, and guidance from the European Patient Forum and European policymakers a number of interactions are planned over the coming years. Example interactions will leverage both GRIDD and awareness campaigns to access and continue the dialogue around dermatological diseases across the entire continent of Europe.



Continued Support Initiatives:



Sharing Platform

Online repository of all resources from internal and external stakeholders within the Members Hub on the GlobalSkin website. Example: access E-learn materials, community initiatives at all levels, and toolkits for an awareness campaign. The one-stop shop for community digital resources. The sharing platform development is ongoing over the arching project designed to allow community members to share best practices with internal stakeholders. This capacity-building platform will house the resources developed by GlobalSkin-Europe and Community Members. The archive is a resource that is designed to increase community strengthening and joint action pillars.

Funding Resource Information

Community members of GlobalSkin-Europe expressed funding as a key barrier to success and indicated the need for support in this area. To help with this need, GlobalSkin-Europe plans to provide information on the latest calls and resources that could help Community Members with their own funding efforts.

Outcomes

- The community engagement outcomes build year on year. To align with the resource availability outcomes are agile.
- Small incremental steps lead to a larger overarching goal of enabling GlobalSkin-Europe to unite with a single voice and take a place at the top of health policy in Europe.



2022

- **Develop ideas for an awareness campaign**
- **Start a conversation with policymakers about skin disease**
- **Promote GRIDD awareness outside of the GlobalSkin-Europe Community**

Developing ideas for an awareness campaign, in conjunction with that of the Global Dermatology Coalition, that will include the results of discussions with different partners on the timing and concept of the European Skin Disease Awareness campaign.

Starting a conversation with policymakers around skin diseases, including accentuating the importance of dermatological diseases in these debates, organizing panel discussions on relevant topics with different stakeholders, and getting actively involved in the EU Health Policy Platform. Promoting GRIDD awareness outside the GlobalSkin Community includes highlighting GRIDD data within the framework of different dialogues and discussions.



2023

- **Deliver E-Learn Sessions**
- **Deliver Awareness Campaign**
- **Be present and active in the European health discussion**



E-learning sessions will be developed to address the greatest needs of the community. These sessions will provide the opportunity to highlight internal partners' initiatives and learn insight from external stakeholders on the issues most pertinent to the community.

Following the 2022 development of the awareness campaign, in conjunction with that of the Global Dermatology Coalition, the planned launch of the campaign will provide resources for GlobalSkin-Europe that lay the groundwork for discussions with external stakeholders building traction around the campaign.

Create opportunities to have people and communities living with dermatological conditions or skin traumas take a seat at the table in discussion on all health policies across Europe both within and outside the EU. The GRIDD data is a rich unique source of insight based on gathering patients' views on the impact of their disease. This allows a differing conversation with partners across the European health ecosystem.



2024

- **Increased growth and engagement of the GlobalSkin-Europe Community**
 - **Sustained growth in Awareness Campaign across Europe**
 - **Present and active in European health discussion**
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Seek and facilitate opportunities to allow community combined partnership projects. As the community grows the aim is to increase the united voice and understanding among the leaders in health in Europe that dermatology patient organizations are key partners.

Following on from the launch of the Awareness Campaign we shall see a 10% growth in engagement with both internal and external stakeholders. The measure can be gathered from social media, participation numbers, and status level of partnership e.g. high ranking partnership with EU/Europe policymakers.

Increased invitation to discuss and provide insight via GRIDD data for policy discussion across regional, national, and Europe levels.

References:

1. [The Global Burden of Skin Disease in 2010: An Analysis of the Prevalence and Impact of Skin Conditions](#)
2. [Burden of skin disease and associated socioeconomic status in Europe: An ecologic study from the Global Burden of Disease Study 2017](#)