

ADVOCACY



PID LIFE INDEX
IPOPI

How to use the PID Life Index

INTERMEDIATE

→ THE PID LIFE INDEX CAN BE USED AS A VERY POWERFUL ADVOCACY TOOL BY PATIENT REPRESENTATIVES, MEDICAL PROFESSIONALS, AND ANY OTHER STAKEHOLDER INTERESTED IN SPEAKING ABOUT PIDS IN A GIVEN COUNTRY. VISIT THE WEBSITE [HERE](#).

OBJECTIVES:

- Speak about the **situation of the PID community** in a given country and/or world region with first-hand data.
- Gain an understanding of the **differences existing in the countries** when it comes to caring for and managing patients with PIDs.
- **Raise awareness about a specific Principle of Care for PIDs** amongst the wider society, policymakers, medical professionals, and other relevant stakeholders.

ADVANTAGES:

- **Credibility:** Real data enhances your argument's trustworthiness.
- **Infomed Decisions:** Stakeholders rely on accurate data for choices.
- **Impactful Advocacy:** Real data reinforces advocacy, making it compelling.

STEP BY STEP:

1 DEFINE YOUR GOAL

1 Clearly determine what you **aim to achieve**, whether it's improved diagnosis, better treatment, or other specific objectives.

2 KNOW YOUR AUDIENCE

2 Understand your target audience – whether doctors, policymakers, or the general public – and **adapt your message to address their specific interests and concerns**.

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STEP BY STEP:

3

USE THE IPOPI PID LIFE INDEX WISELY

The Index is versatile, serving different needs. You may use it to make comparisons between a given country and the region to which belongs or to explain a specific principle in different facets.

The information is displayed in a manner that you can adapt to your needs:

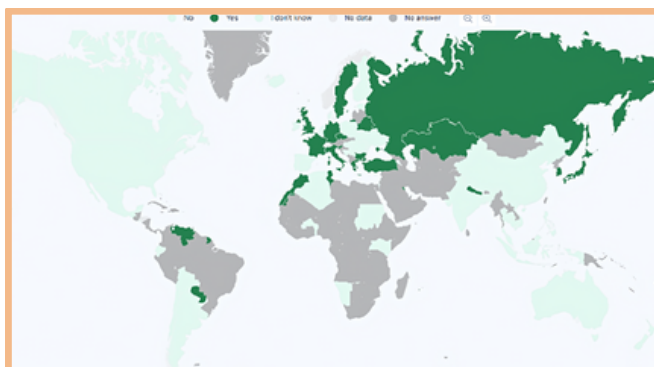


Pure data to be given in a conversation.

For example:

Country X has only 15% of the diagnostic tools available to patients with PIDs.

Have a look at the [website](#) to discover the endless possibilities of the PID Life Index.



The world map can be displayed in a presentation to showcase one specific aspect that is of interest to you.

For example:

The existence of national registries for PIDs remain a challenge for a majority of countries in the world.



You can also choose to have the countries displayed in a ranking on the basis of all the principles or just a selected one to put an emphasis on where a given country stands

For example:

A graphic visualisation of a given country allows to show how well / how poorly the country does on a certain aspect.

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STEP BY STEP:

4 CRAFT A STRATEGY

Develop a clear plan on how to present the PID Life Index data. Consider using impactful visuals, infographics, and real patient testimonials to make the data relatable and understandable.

5 ENGAGE YOUR COMMUNITY

Mobilise your community of patients, families, and supporters. Encourage them to participate in your efforts and be vocal advocates. **A united front strengthens your cause.**

6 SOCIAL MEDIA AMPLIFICATION

Leverage social media platforms to share the PID Life Index findings, patient stories, and advocacy messages. Engage with influencers and relevant organisations to expand your reach.

7 KEEP PERSISTENT

Advocacy takes time and consistent effort. Stay persistent, continue sharing the data-driven message, and actively engage with stakeholders. **Persistence often leads to positive change.**

TIP

- When discussing a country's situation with policymakers, medical professionals, or stakeholders, merely explaining the circumstances may be insufficient. Comparing the country to similar nations in the region can be more effective in making the case.
- For more details, consult "[What is the PID Life Index](#)" in the Toolkit.