

RESEARCH AND DATA COLLECTION



What is the PID Life Index?

BEGINNER

→ THE PID LIFE INDEX IS AN INTERACTIVE TOOL DEVELOPED BY IPOPI THAT CONTAINS DATA THAT PICTURES HOW IT IS TO LIVE WITH A PID IN A COUNTRY OR REGION. VISIT THE WEBSITE [HERE](#).

HOW WAS THE PID LIFE INDEX BEEN BUILT?

The PID Life Index gathers information submitted voluntarily by IPOPI national member organisations and by medical contacts.



The Index is structured around the six PID Principles of Care:

- **Diagnosis:** Aims at **identifying whether the different types of diagnosis are available in a given country**, including: genetic, biological, prenatal diagnosis, newborn screening for SCID, and diagnosis rate.
- **National patient organisations:** Shows organisations that **represent primary immunodeficiencies in a specific country** and are a **member of IPOPI**.
- **Registries:** Shows proportion of affected individuals among the general population (**prevalence**) as well as measuring the number of new cases diagnosed each year (**incidence**), diagnostic rates, delays, and study of specific populations or conditions.
- **Treatments:** Aims at showing the **different types of treatments available in a given country**, including: anti-infectious, immunoglobulin therapies, vaccines, biological and targeted therapies, curative treatments.
- **Universal health coverage:** Shows the **level of coverage of a given diagnostic tool or treatment for patients with PIDs**.
- **Specialised centres:** Shows the **existence of centres specialised in the treatment of patients with PIDs** for adults and/or for children, including their collaboration as a network in a country, services specialised in adults with PIDs and on transition of care.

What is the PID Life Index?

OBJECTIVES:

The PID Life Index website provides information on PID-related topics including:

- **Geographical visualisation** ([world map](#)) of how countries perform in the 6 PID Principles of Care or in the ones selected by the user.
- **Index visualisation** of how countries or regions selected by the user perform in the 6 PID Principles of Care or in the ones selected by the user.
- A **country page** in which all the PID related information is displayed.
- Geographical display of the **specialised PID centres for children or/and adults**.
- **Database** with the **immunoglobulin replacement therapies** that have received a marketing authorisation.
- A **glossary** that explains the main terms used.
- A **list of publications** related to the PID Life Index and the 6 PID Principles of Care.

STEP BY STEP:

1

DEFINE YOUR SEARCH'S PURPOSE

- There is a lot of information available on the PID Life Index. When using it, just **think first about the type of information you need and how it could be better displayed** (in a map, through the data visualisation, as a figure...).

What is the PID Life Index?

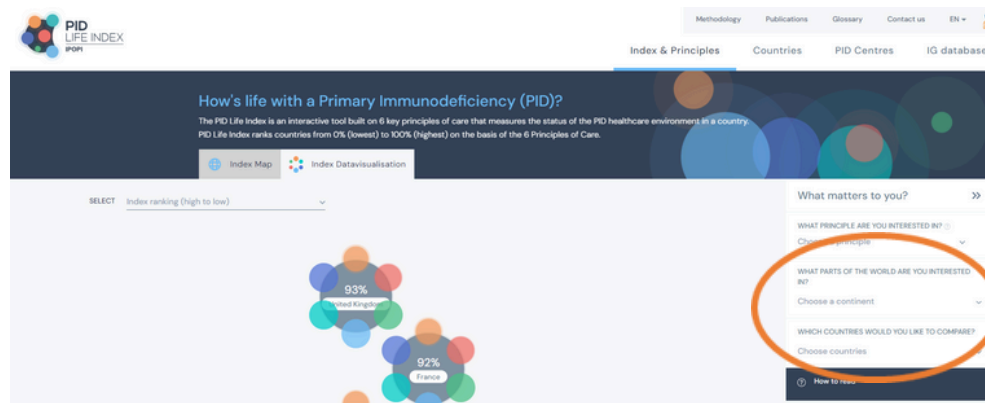
STEP BY STEP:

2 REFINE YOUR SEARCH

- To know more about a specific Principle of Care:
 - check the “What matters to you?” panel on the right inside to filter the information to be displayed.



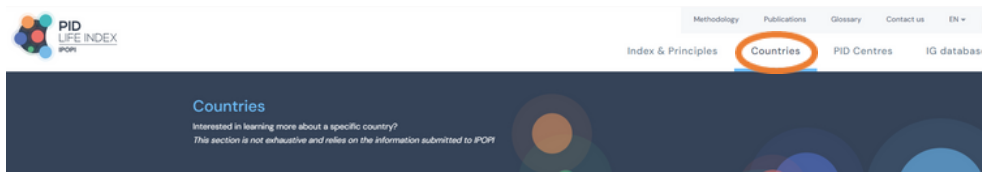
- To have more information about just for one (or two) world region(s) (i.e. South East Asia or Europe, for instance)
 - go to “Index Datavisualisation” and then on the right inside select the part of the world (within the “What matters to you” panel) you are interested in.



What is the PID Life Index?

STEP BY STEP:

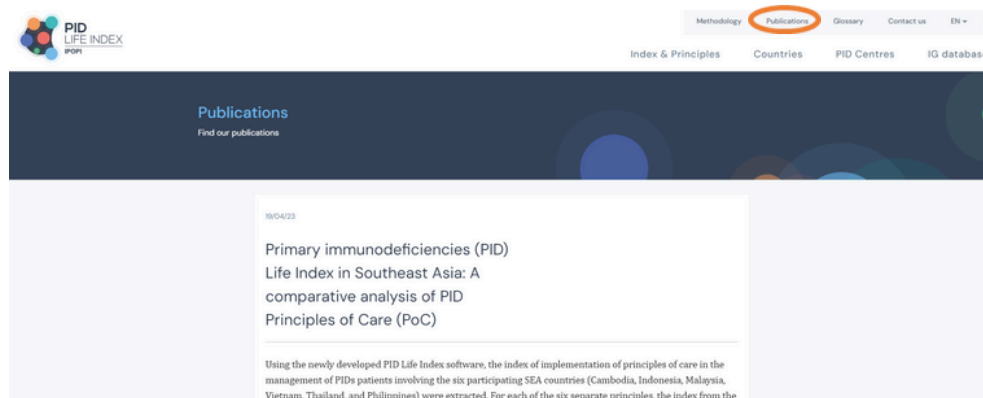
- To know more about a specific country:
 - select the indent “Countries” in the upper part of the screen and select the country from the list of countries displayed or by typing its name in the search.



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DEEPEN YOUR KNOWLEDGE

- The PID Life Index website also contains a series of publications in journals that could be of interest, do not forget to check them!



IS YOUR COUNTRY MISSING?

To learn more about how you can contribute to this project, contact Leire Solis, IPOPI Health Policy and Advocacy Senior Manager, at leire@ipopi.org