



## Campaign messaging

# Turning real-world data into knowledge for better PID care

Improving access to diagnosis, treatment  
and care for PID patients through  
collaborative & real-world data use

# Key Messaging

## Diagnosis

Data helps improve knowledge & understanding of PIDs, which is crucial to ensure timely diagnosis.



Globally, over 6 million people are affected by primary immunodeficiencies, among which 70 to 90% remain undiagnosed.<sup>1</sup>

Collecting & sharing data on PIDs can support greater knowledge about the disease and facilitate testing and early diagnosis; and the development of efficient diagnostic tools.

For instance, the analysis of national registries and health records data may allow to identify affected individuals within the general population and study specific populations at risks.

Interconnected databases are crucial to improve genetic testing and help make better informed decisions about PID care across regions.

1. Meyts I, Bousfiha A, Duff C, Singh S, Lau YL, Condino-Neto A, Bezrodnik L, Ali A, Adeli M, Drabwell J. Primary Immunodeficiencies: A Decade of Progress and a Promising Future. Front Immunol. 2021 Feb 18;11:625753. doi: 10.3389/fimmu.2020.625753. PMID: 33679719; PMCID: PMC7935502.

## Treatment & Care

Data allows to enhance care and deliver improved or new treatments, leading to better patients' health outcomes and enhanced quality of life.



Turning quality data into clinical insights and medical evidence contributes to more efficient, higher quality, safer and more personalized care; and help advance treatment options

Data collected and analysed through registries and other sources provide important information about patients, the impact, efficacy and durability of treatment overtime to strengthen their care, as well as help decision makers improve health systems

## Research & Innovation

Health data informs and advances scientific and medical research & drives innovation. Research & innovation also help generate evidence to support change in policies and practices for the benefit of PID patients.



Global collaboration and data sharing is the key to enhance understanding of PIDs and develop new successful treatments to improve patients' lives.

Data from clinical trials and other sources help advance understanding of PIDs. Data collection and sharing is crucial to develop innovative therapies and make these therapies accessible to all PID patients. Global collaboration on data sharing will help address remaining unmet needs of PIDs across regions in order to access all the information required to minimize uncertainties on the benefits and shortcomings.

## Medical Education

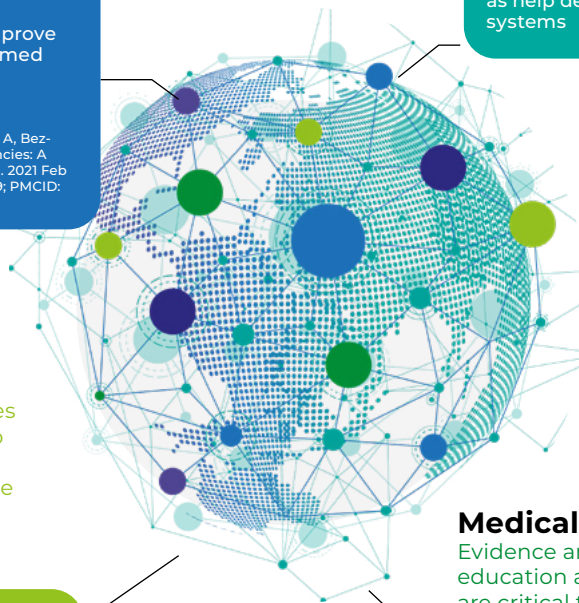
Evidence and science-based medical education and best practices exchange are critical to progress clinical care worldwide.



Data helps reduce the knowledge gap among primary care physicians and specialists and help reduce disparities in PID awareness across the globe.

Improving awareness and education for health professionals and specialists through evidence-based data is important to strengthen expertise, which will allow accurate diagnosis and treatment of PIDs

Continuous medical education is fundamental as it helps align practice with the evolution of scientific and medical knowledge



# Summary narrative

Robust, quality health data is critical to enhance disease knowledge, healthcare delivery, medical research and development, support policy and regulatory decisions; and ultimately benefit patients as well as societies.

In rare diseases like PIDs, data is all the more vital to provide more efficient, higher quality, safer and more personalised care.

Data can change lives by speeding up diagnosis, improving patient care, and fostering research into new treatments.

World PI Week 2023 is shining a light on the value of data in the field of PIDs, for the diagnosis of PIDs, treatment and care, research, innovation and medical education.

## Our policy calls

What needs to be done worldwide



**Leveraging real-world evidence including patient-reported outcomes data** to inform priorities for research, regulatory decisions, and monitoring & follow-up on efficacy of treatment and health outcomes



**Robust and up-to-date national PID registries & comparable collection of data in all countries** – to provide necessary data for planning services, monitoring public health, improve PID research, diagnosis and care



**Ethical, responsible and transparent use of patients' health data** – to ensure data obtained from patient registries is used and shared safely to improve understanding and care for PIDs



**Collaboration and sharing of research data & results** in the academic sector and beyond among all relevant stakeholders, to benefit patient's health.



**Worldwide efforts to strengthen the collection of data and to shape collaborative health data ecosystems** – to provide the knowledge vital for higher quality and more personalized care



**Using health data to facilitate innovation** in diagnosis, treatment and research; and to **enhance health systems** and specialist care services for PIDs



Join World PI Week and  
help bring about change for  
primary immunodeficiency  
patients worldwide

