

Patient centred-care in primary immunodeficiency

5 KEY Principles

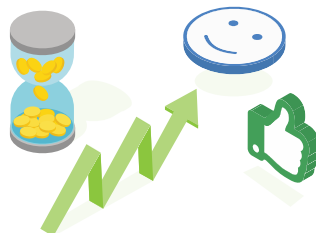
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- There are over **320 different types** of primary immunodeficiencies, estimated to affect over 6 million people worldwide.
- A **personalised approach** and treatment pathway is required to treat patients.
- **Immunoglobulin therapies** are not generic medicines and should be personalized on the basis of tolerability, ease of access and lifestyle criteria.
- **Gene therapies** and **bone marrow transplants** are therapeutic options for most severe cases of primary immunodeficiency but are not available in all countries and not all patients are suitable candidates.
- **Antifungals, antivirals and antibiotics** are a critical part of treatment. Doctors evaluate the needs and types of treatment for each patient, based on clinical history, examination and laboratory results.

Creating value

Benefits of patient-centred care include shared decision-making, improved **health outcomes**, improved **patient satisfaction** and **cost savings** for healthcare systems.



Working with patients – not around

- During their journey, many patients and caregivers become familiar with the complexities of the disease, limitations and benefits of the health-care system they encounter. Their input and experience is essential to successful medical management.
- Healthcare professionals have a key role to play in **ensuring that all patients are adequately educated and included as partners** in medical decision-making.

Involving multiple actors

A **multi-disciplinary approach to patient care** is inclusive of all actors who play a role in care delivery, from patients, families and doctors, to allied health-care professionals, biologists and researchers; and bridges health and social services.



Patient benefit is the end goal of care

Patient centricity means that healthcare and healthcare systems are designed to ultimately benefit patients.

- **Newborn screening** for severe forms of primary immunodeficiency is one example of this, by ensuring that patients can be diagnosed at an early stage.
- **Disease-specific registries** are important tools to expand knowledge and improve screening, diagnosis and care of patients.

