WHA Resolution on Rare Diseases Discussion Paper

What is the WHA Resolution?

The World Health Assembly (WHA) Resolution on Rare Diseases is an **official policy tool** that was adopted by the WHA in Geneva in May 2025. It requests the World Health Organization (WHO) to develop a Global Action Plan on Rare Diseases by the 81st World Health Assembly, which will take place in May 2028.


World Health Organization

Seventy-eighth World Health Assembly

Rare diseases: a global health priority for equity and inclusion

The WHA Resolution on Rare Diseases recognizes rare diseases as a global health priority at the highest level and has the potential to improve diagnosis, treatment, care and support for Persons Living with a Rare Disease (PLWRD).

What is a Discussion Paper?

A discussion paper is an official, provisional document published by the WHO to:

gather feedback

stimulate discussion

build consensus

It will allow the WHO secretariat (staff) to share its thinking on the upcoming GAPRD with the rare disease community and collect their feedback.

What does the Discussion Paper include?

The Discussion Paper is divided into 6 sections. The first 5 contain the proposed background, scope, vision, goal and guiding principles for the GAPRD. The last section is the most important as it outlines areas for action for countries, WHO and other stakeholders.

Background

The background section provides a summary of the shared challenges for people living with rare diseases around the world.

Scope

This section explains what the GAPRD is supposed to do (in scope) and what it is not intended to do (out of scope).

In Scope

The action plan will:

- **address rare diseases collectively**
- **underline systemic barriers**
- **highlight shared challenges**
- **outline system-level actions that can be adapted to national contexts and capacity**

Out of Scope

The action plan will **not:**

- try to be a comprehensive catalogue of rare diseases
- address condition-specific or country-specific challenges

Vision

A world in which people living with a rare disease:

- **attain the highest possible level of health and well-being**
- **fulfil their potential**
- **have equal rights, opportunities, dignity, respect, and autonomy**

Goal

Improve the lives of people living with a rare disease, their families and caregivers by

- **reducing stigma and discrimination**
- **preventing avoidable mortality and morbidity**
- **advancing equitable, timely, affordable, and sustainable diagnosis, treatment and care**

Guiding Principles

- People-centric universal health coverage
- Integrated and life-course approach to care
- Evidence-informed policy and practice
- Intersectoral and multistakeholder collaboration
- Empowerment of people with lived experience
- Equity and human rights

Action Areas

- Governance & Sustainable Financing
- Diagnosis and Treatment
- Integrated and Networked Care
- Research and Innovation
- Data and Monitoring
- Empowerment, Participation & and Support

How can I share my feedback on the Discussion Paper?

It is important for the global community of PLWRD and their families to respond to the consultation with a strong collective voice. To support meaningful and structured input, RDI has developed a short online survey with targeted guiding questions. These questions will help members of our community reflect on the relevance, feasibility and implementation of the proposed measures, identify gaps, and suggest improvements. They will also guide discussions led by the RDI Regional Task Forces over the next month.

RDI will gather the community's feedback and prepare a set of recommendations for the WHO. These recommendations will be shared in a webinar to gather final input. Then RDI will share this consolidated feedback with the WHO.

What Happens Next?

Here is a timeline of the next steps for the Discussion Paper and the Global Action Plan on Rare Diseases:

JAN 2027 → WHO publishes comments received on discussion paper

MAR-APR 2027 → WHO develops 10-year GAPRD and opens consultation

JAN 2028 → Draft GAPRD considered by the WHA Executive Board

MAY 2028 → Consideration of GAPRD at the 81st World Health Assembly