

Webinar on Health Financing & Social Health Protection for Rare Diseases

5 November 2025, 14:00 – 16:00 (CEST)

On-line, MS Teams

Background

Rare diseases affect more than just health: they are often a source of significant financial hardship. Individuals with rare diseases face high, often catastrophic, out-of-pocket payments for medical care. Together with travel expenses and lost income for both people living with rare diseases and their caregivers, these costs present a massive financial burden for many households.

Rare Diseases International (RDI) and the P4H Network have partnered to enable global advocacy and collaboration to influence and support innovation in health financing arrangement and social health protection that concretely promote effective health coverage, increased access and adequate financial protection for people living with rare diseases. The collaboration aims to investigate the scope, issues, needs, and existing approaches and to frame members' interests and actions within a global perspective to promote best practices at all levels.

RDI and P4H contacted RDI member organizations, P4H country focal persons, experts with the World Health Organization (WHO), consultants with the Organisation for Economic Co-operation and Development (OECD) and professionals to exchange information on national experiences in financing of rare diseases treatment. This information and preliminary data were reviewed and validated to develop a shortlist of countries from different regions. Then, the rare disease situation in 11 countries — including Australia, China, Colombia, Costa Rica, Côte d'Ivoire, France, India, Kazakhstan, Russia, Tanzania, and Thailand — was documented through questionnaires and structured interviews with primary sources.

This cross-country study explores the current health financing arrangement and social health protection structure for rare diseases, existing challenges and plans for policy action in each country and region. The findings are intended to serve to inform global and national policy initiatives related to universal health coverage and rare diseases and to provide opportunities to reduce financial hardship and enhance quality of life for people living with rare diseases and their families around the world.

This webinar will introduce the RDI-P4H collaborative project and its objectives, present the preliminary results and recommendations, discuss the significance of the results among experts, and collect perspectives, comments and insights from participants and presenters to share and further refine the draft article on findings prior to its submission for publication.

Webinar Objectives

The objectives of this webinar are as follows:

- Introduce the project and its objectives
- Present the preliminary results and findings, as well as the initial call-to-action and recommendations
- Discuss the significance of the results among experts in health financing
- Collect reactions and perspectives from audience members
- Receive feedback and insight to further refine the initial manuscript prior to publication

Audience

This is a public webinar, so the audience will be any interested members of the public. RDI will target its invitations to their members, partners, and their social media community. P4H will share the invitation with all of their network.

The webinar should be of particular interest to experts in health financing or social health protection measures, particularly in the rare disease space, and those working on innovative funding models.

Agenda

Time	Item
14:00-14:05	Welcome & Housekeeping: Alanna Miller, RDI
14:05-14:10	Introduction & Opening Remarks: Claude Meyer, WHO & Alexandra Heumber Perry, RDI
14:10-15:00	Overall Findings of the Analysis of 11 Countries on Health Financing and Social Health Protection for Rare Diseases: Aungsumalee Pholpark, P4H (20 minutes) Health Financing and Social Health Protection for Rare Diseases: Achievement and challenges from the selected case studies China (Finn Guo, the Illness Challenge Foundation) (10 minutes) France (Salma Khalfi, CNAM) (10 minutes) Kazakhstan (Ainur Aiypkhanova, Scientific-Technical Council of the Ministry of Health, Kazakhstan) (10 minutes)
15:00-15:10	Q&A
15:10-15:45	Panel Discussion Moderator: Alexandra Heumber Perry, RDI Panelists: Susan Horton, University of Waterloo Lou Garrison, The Comparative Health Outcomes, Policy, and Economics (CHOICE) Institute; Department of Pharmacy, University of Washington; Office of Health Economics Claude Meyer, WHO Joseph B. Babigumira, GHE Consulting
15:45-15:55	Q&A
15:55-16:00	Final wrap-up & Next steps: Alexandra Heumber Perry, RDI