

WHO, RDI & Rare Diseases

WHO and Rare Diseases:

- WHO Director General Statement on Rare Diseases, February 2018
- RDI Meeting with Dr Tedros, WHO Director General, Geneva, March 2019
- UN Political Declaration on Universal Health Coverage includes Rare Diseases, September 2019, and, WHO is responsible for the implementation of UHC
- Memorandum of Understanding (MoU) signed between WHO and RDI, December 2019



WHO, RDI & Rare Diseases

WHO - RDI MoU two main specific areas of collaboration 2020 – deliverables December 2020:

- WHO Collaborative Global Network for Rare Diseases: Need Assessment Study
- WHO Framework of operational descriptions for rare diseases and key figures, to inform WHO and Member states when considering policy shaping and implementation



Other areas of collaboration between WHO and RDI:

- International Classification, codification and implementation in healthcare system (linked to Orphanet and to INSERM ICD)
- List of Essential Diagnostic Tools and of Essential Medicines

Memorandum of Understanding (MoU)

Article 1

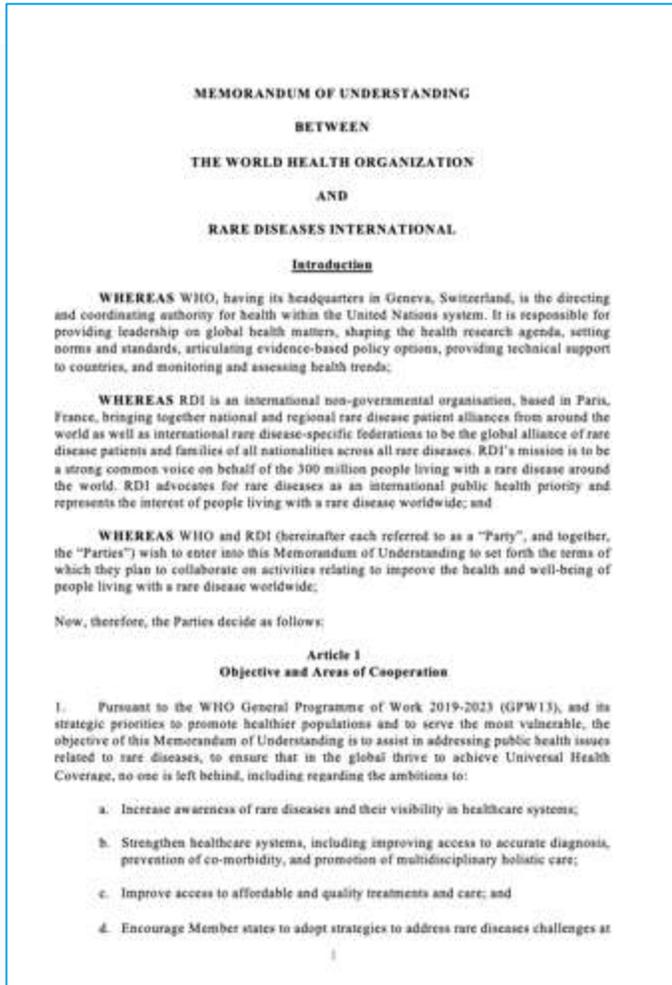
Objective and Areas of Cooperation

1. Pursuant to the WHO General Programme of Work 2019-2023 (GPW13), and its strategic priorities to promote healthier populations and to serve the most vulnerable, the objective of this Memorandum of Understanding is to assist in addressing public health issues related to rare diseases, to ensure that in the global thrive to achieve Universal Health Coverage, no one is left behind, including regarding the ambitions to:

- a) Increase awareness of rare diseases and their visibility in healthcare systems;
- b) Strengthen healthcare systems, including improving access to accurate diagnosis, prevention of co-morbidity, and promotion of multidisciplinary holistic care;
- c) Improve access to affordable and quality treatments and care; and
- d) Encourage Member states to adopt strategies to address rare diseases challenges at national level within an international policy framework.



Specific objectives in MoU (1)



Source: ¹Article 2.b.: Memorandum of Understanding between The World Health Organization and Rare Diseases International

“Healthcare systems strengthening through global networking of specialised expertise¹:

“WHO and RDI will collaborate to improve the organisation of health care services by proposing to establish, as appropriate, a global network of multidisciplinary specialised expert centres for rare diseases, in a structure approach grouping rare diseases by therapeutic areas, so to be inclusive of all rare diseases, to leave no one behind.”

“WHO and RDI will prepare a need assessment study so to propose the conceptual and methodological framework for the network with a strategic, bottom up approach that promotes the identification and support of highly specialised multi-disciplinary centres of expertise, connects centres of expertise regionally and internationally into WHO collaborative global networks for rare diseases while encouraging local capacities to generate additional expertise”



WHO-RDI MoU: Specific Objectives (2)

MEMORANDUM OF UNDERSTANDING

BETWEEN

THE WORLD HEALTH ORGANIZATION

AND

RARE DISEASES INTERNATIONAL

Introduction

WHEREAS WHO, having its headquarters in Geneva, Switzerland, is the directing and coordinating authority for health within the United Nations system. It is responsible for providing leadership on global health matters, shaping the health research agenda, setting norms and standards, articulating evidence-based policy options, providing technical support to countries, and monitoring and assessing health trends;

WHEREAS RDI is an international non-governmental organisation, based in Paris, France, bringing together national and regional rare disease patient alliances from around the world as well as international rare disease-specific federations to be the global alliance of rare disease patients and families of all nationalities across all rare diseases. RDI's mission is to be a strong common voice on behalf of the 300 million people living with a rare disease around the world. RDI advocates for rare diseases as an international public health priority and represents the interest of people living with a rare disease worldwide; and

WHEREAS WHO and RDI (hereinafter each referred to as a "Party", and together, the "Parties") wish to enter into this Memorandum of Understanding to set forth the terms of which they plan to collaborate on activities relating to improve the health and well-being of people living with a rare disease worldwide;

Now, therefore, the Parties decide as follows:

Article 1 Objective and Areas of Cooperation

1. Pursuant to the WHO General Programme of Work 2019-2023 (GPW13), and its strategic priorities to promote healthier populations and to serve the most vulnerable, the objective of this Memorandum of Understanding is to assist in addressing public health issues related to rare diseases, to ensure that in the global thrive to achieve Universal Health Coverage, no one is left behind, including regarding the ambitions to:

- a. Increase awareness of rare diseases and their visibility in healthcare systems;
- b. Strengthen healthcare systems, including improving access to accurate diagnosis, prevention of co-morbidity, and promotion of multidisciplinary holistic care;
- c. Improve access to affordable and quality treatments and care; and
- d. Encourage Member states to adopt strategies to address rare diseases challenges at

“ 2. The Parties intend to collaborate in the following preliminary overarching themes for this Memorandum of Understanding:

a) *Data sharing to improve the recognition of rare diseases and their visibility in health systems*

WHO and RDI will develop an operational description of rare diseases and key prevalence or incidence figures that may inform WHO or Member States when considering national, regional and global policy shaping and implementation.”



WHO CGN4RD – The Vision

WHO Collaborative Global Network for Rare Diseases (WHO CGN4RD) connect major academic healthcare organizations (hubs) with multi-disciplinary rare disease specialist capacities, at a regional and global levels.

This initiative contributes to the implementation of [Universal Healthcare Coverage](#) world-wide and to [strengthen healthcare systems](#) within current available resources.

Within the [SGDs Agenda 2030](#), the ambition is to make this Global Network potentially available to [serve 2 billion people with hubs in major cities](#) (hence about 85 million people living with a rare disease), specifically:

- [To break down the traditional barriers in accessing care](#) often experienced by patients and their families, [through open, direct self-referral](#) to the Network's Global RD Hubs as much as through potential healthcare pathways
- [To expedite and provide accurate diagnosis](#), reducing the time to diagnosis and the misdiagnosis, hence addressing the diagnostic odyssey to less than one year after the first contact with a medical doctor
- [To access holistic, affordable and quality highly specialised healthcare](#) for diagnostic, care and prevention of co-morbidities

Dr Rüdiger Krech, WHO Director, Health Promotion

Division of Universal Health Care & Healthier Populations



The video player shows Dr Rüdiger Krech, WHO Director, Health Promotion, speaking in front of a blue background with the WHO logo and text. The video title is 'Ruediger Krech' and the channel is 'World Health Organization'. The video is at 0:13 / 5:40. The video player interface includes a play button, volume icon, progress bar, and YouTube logo.

Vision:

- Experts offer acute advice and organisation of care in patient crisis
- Virtually present at the bedside and at home
- 'Top-notch' research players
- World renowned training centres offering training opportunities
- Exploit advancements in technology and innovation

<https://www.youtube.com/watch?v=ap0iM3LZfqQ>



RARE
DISEASES
INTERNATIONAL