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 strive 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)

"Healthcare systems strengthening through global networking of specialised expertise!":

"WHO and RDI will collaborate to improve the organisation of health care services by proposing to establish, as appropriate, a global network of multidisciplined 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)

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.”

Source: 1Article 1.2.a.: Memorandum of Understanding between The World Health Organization and Rare Diseases International
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.

Source: If you need to add a source or footnotes to a slide you can do so here.
Dr Rüdiger Krech, WHO Director, Health Promotion
Division of Universal Health Care & Healthier Populations

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