



Briefing Package:

Campaign on Universal Health Coverage for Rare Diseases

#UHC4RareDiseases

About the #UHC4RareDiseases Campaign

An important milestone in the lead up to Rare Disease Day is the **Universal Health Coverage Day on 12 December**. This is the global awareness day to ask for the implementation of the commitments made towards UHC at national and global level.

The long-term goal of Rare Disease Day over the next decade is equity for people living with a rare disease and their families. **Universal Health Coverage is a safeguard of equity** and, as a community, we must make sure people living with a rare disease are included in national strategies for UHC and essential health service packages.

This campaign aims to create awareness and momentum among policy-makers and other relevant stakeholders on the fact that **UHC will not be truly universal unless it addresses the needs of the rare disease population**.

The purpose of this briefing

This briefing is **targeted towards rare disease advocates** as a background document and provides:

1. The globally recognised definition of UHC
2. A summary of the commitments that Member States have signed with regards to UHC implementation that are relevant to rare diseases.
3. Guidelines on how to get involved in the #UHC4RareDiseases campaign.

Other tools available to you

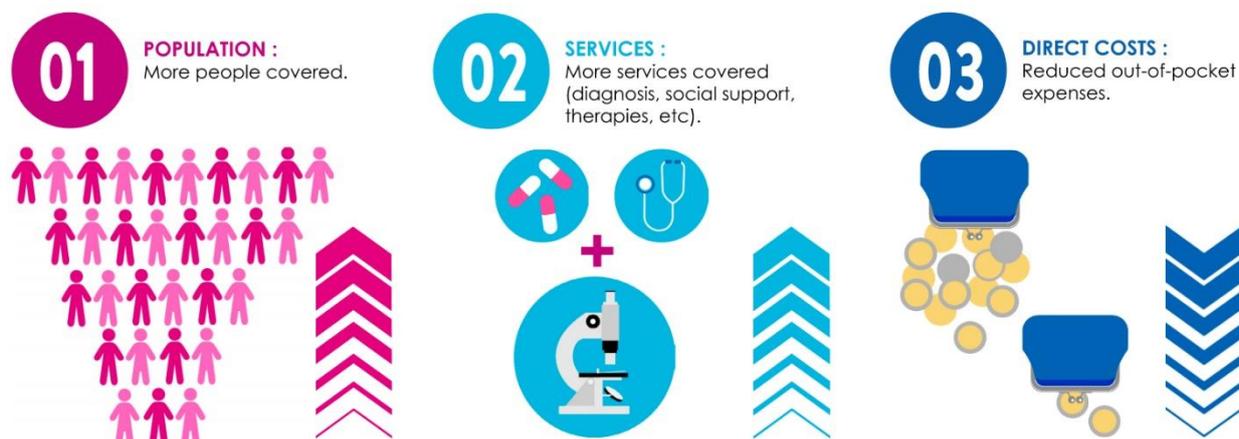
Rare disease advocates are encouraged to engage in the #UHC4RareDiseases campaign. They can do this through a number of actions, depending on the time and resources available to them. EURORDIS and RDI have prepared the following materials to help spread the word on the campaign:

- **A social media toolkit:** this includes examples of posts that can be shared on Twitter, Facebook, LinkedIn, as well as webpages.
- **A factsheet on how national authorities can move towards UHC by addressing the needs of the rare disease population** – this can be shared widely on social media, websites, with policy-makers. There is also an editable version so that national disease groups can translate it and adapt it to their specific demands at national level.
- **A template letter to be sent to policy-makers:** this can be used to reach out to national contacts at the Ministry of Health (two models available with RDI/EURORDIS logos).

ABOUT UNIVERSAL HEALTH COVERAGE (UHC)

Universal health coverage (UHC) ensures all people, everywhere, can access the quality essential health services they need without being exposed to financial hardship. UHC includes three dimensions of coverage: in terms of population, in terms of services and in terms of proportion of costs covered.

THE THREE DIMENSIONS OF UNIVERSAL HEALTH COVERAGE



Adapted from [WHO \(2014\) Making fair choices on the path to universal health coverage: Final report of the WHO Consultative Group on Equity and Universal Health Coverage](#)

UHC is firmly rooted in the **right to health** and requires strong political leadership. Achieving UHC is essential for inclusive development, prosperity, gender equality and fairness. It is one of the **smartest investments** countries can make, and nearly all - including low income countries - have the capacity to mobilise some resources to achieve UHC in the medium and long-term.

ABOUT UHC DAY

Every year on **12 December**, advocates worldwide mobilize on [International Universal Health Coverage Day](#) to call for strong, equitable health systems that leave no one behind. The day is coordinated by [UHC2030](#) and includes events worldwide as well as a big social media campaign.

ABOUT THE UNITED NATIONS POLITICAL DECLARATION ON UHC

On 23 September 2019, a United Nations High-Level Meeting (UN HLM) on UHC was convened by the UN General Assembly (UNGA), which is the main decision-making body of the UN. The [UN Political Declaration on UHC](#) was adopted then by **all** the 193 UN Member States and specifically mentions rare diseases

This is the most comprehensive and ambitious declaration on health in history. It is a commitment that places UHC at the heart of the 2030 Agenda for Sustainable Development. It recognises that UHC is essential to achieve the Sustainable Development Goals, related not only to health but also other spheres:



In addition, the UN Political Declaration emphasised the need to give special attention to the poor, vulnerable, and marginalized segments of the population. This is in line with the principle of “leaving no one behind” which is articulated in the SDG agenda as “reach the furthest behind first”.

As such, **UHC will not be truly universal unless the needs of persons living with a rare disease are addressed.** In fact, targeted national policies for rare diseases can contribute to a government’s efforts towards UHC. Demonstrating the added value of including rare diseases to governments can secure benefits for the global rare disease community as it increases the chances for national policies and resources to address the challenges of rare diseases. More information available in RDI’s [position paper on UHC](#).

Main commitments in the UHC Political Declaration relevant to rare diseases

In order to hold all the 193 UN Member States accountable and call for a UHC that is inclusive of rare diseases, it is important to understand the commitments that they have made. [UHC2030](#), the multi-stakeholder platform advocating for increased political commitment to UHC led by WHO and the World Bank, created a useful document which summarises the main commitments included within the UN Political Declaration. Available [here](#).

These are the most significant commitments for the rare disease community which can be used as reference points in your advocacy efforts:

- **Key commitment including rare diseases in UHC:**

Article 34. Strengthen efforts to address [...] rare diseases [...] as part of universal health coverage

- **Other important commitments:**

Article 25 ensures the best personalised care for all throughout the life course:

“Implement the most effective, high-impact, quality-assured, people-centred, gender and disability-responsive, and evidence-based interventions to meet the health needs of all throughout the life course;”

Article 70 commits to reaching the most vulnerable populations first:

“Ensure that no one is left behind, with an endeavour to reach the furthest behind first, empower those who are vulnerable or in vulnerable situations and address their physical and mental health needs, including all children, youth, persons with disabilities, people living with HIV/ AIDS, older persons, indigenous peoples, refugees and internally displaced persons and migrants;”

Article 39 pledges to reduce financial barriers and out-of-pocket expenses, especially for vulnerable populations:

“Pursue efficient health financing policies, to respond to unmet needs and to eliminate financial barriers to access, reduce out-of-pocket expenditures leading to financial hardship and ensure financial risk protection for all throughout the life course, especially for the poor and those who are vulnerable or in vulnerable situations;”

Article 49 commits to equity in access to quality, safe, effective, affordable and essential medicines:

“Promote equitable distribution of and increased access to quality, safe, effective, affordable and essential medicines, including generics, vaccines, diagnostics and health technologies to ensure affordable quality health services and their timely delivery;”

Additional articles that could be used in your advocacy efforts include:

- Health-in-all policies – [article 26](#)
- Prioritization of health promotion and disease prevention – [article 27](#)
- Safe, quality, people-centred health systems – [article 48](#)
- Improved access to health products through transparency of prices – [article 50](#)
- Better legislation and implementation of policies for access to health – [article 57](#)
- Training of workforce that is sensitive to different needs – [article 61](#)
- Strengthen patient involvement in clinical decision-making – [article 65](#)
- Use of digital technologies and innovation – [article 66](#)
- Comprehensive data collection – [article 67](#)
- Universal access to sexual and reproductive health-care services – [article 68](#)
- More inclusive approaches during emergencies – [article 73](#)

Actions you can take in the lead up to UHC Day to advocate for implementation that is inclusive of rare diseases:

- ✓ Share the enclosed factsheet widely to raise awareness of the needs of the rare disease community, especially with policy-makers.
- ✓ Write a letter to a key decision-maker in your community to highlight the importance of addressing the needs of people with a rare disease as part of UHC.
- ✓ Suggest decision-makers to get involved in the social media campaign #UHC4RareDiseases.
- ✓ Hold a UHC Day event that highlights a key local or national policy issue for the rare disease community and invite a key decision-maker.
- ✓ Use media attention on UHC Day to launch a new initiative for the rare disease community.
- ✓ Highlight patient stories on social media with the hashtag #UHC4RareDiseases.

Contact point:

Clara Hervas,
Public Affairs Manager, EURORDIS/RDI
clara.hervas@eurordis.org

Key resources and information

About rare diseases

Use of statistic '300 million people globally living with a rare disease'.

- [Estimating cumulative point prevalence of rare diseases: analysis of the Orphanet database, European Journal of Human Genetics, by EURORDIS-Rare Diseases Europe, Orphanet & Orphanet Ireland.](#)
- [EURORDIS press release: New scientific paper confirms 300 million people living with a rare disease worldwide](#)
- [What is a rare disease webpage \(on rarediseaseday.org\)](#)
- [Dr Tedros tweet 28.02.19](#)
- [Opening Remarks by H.E. Mr. Sven Jürgenson, Permanent Representative of Estonia at the Rare Disease Day Policy Event, New York, 21 February 2019](#)

The impact of rare diseases on daily life

- [EURORDIS position paper: Achieving Holistic Person-Centred Care to Leave No One Behind](#)
- [Rare Barometer survey report on 'Juggling care and daily life: The balancing act of the rare disease community'](#)
- [Rare Barometer survey infographic on 'Juggling care and daily life: The balancing act of the rare disease community'](#)
- [Disability and rare disease: towards person-centred care for Australians with rare diseases, The McKell Institute](#)
- [EURORDIS Factsheet: Most people living with a rare disease are living with disability](#)

Human rights of people living with a rare disease

- [Human Rights Council Resolution on access to medicines and vaccines](#)
- [UN Convention on the Rights of People with Disabilities](#)
- [Report of the Special Rapporteur on the rights of persons with disabilities to 73rd Session of the UNGA.](#)

Rare diseases in the Sustainable Development Goals and universal health coverage

- [Rare Diseases International position paper: Universal health coverage](#)
- [Universal Health Coverage Day campaign toolkit](#)
- [News article, RDI: United Nations human rights body stresses the need to address rare diseases within Universal Health Coverage](#)
- [EURORDIS press release: UN Member States include rare diseases in political declaration on universal health coverage](#)
- [NGO Committee for rare diseases press release: Rare Disease Day 2019 Policy Event at the United Nations](#)
- [NGO Committee for rare diseases event report: Rare Disease Day 2019 Policy Event at the United Nations](#)
- [NGO Committee for rare diseases event report: Global Gathering for Rare Diseases: Inauguration of the NGO Committee for Rare Diseases 2016](#)