RARE DISEASES INTERNATIONAL

EURORDIS RARE DISEASES EUROPE

UNIVERSAL HEALTH COVERAGE FOR RARE DISEASES

#UHC4RareDiseases

FACTSHEET FOR POLICY MAKERS

Why you should take action to ensure universal health coverage in your country or region is inclusive of the needs of people living with a rare disease and recommendations to do so.

ABOUT THE #UHC4RareDiseases CAMPAIGN

UNIVERSAL HEALTH COVERAGE DAY

Run by EURORDIS-Rare Diseases Europe, Rare Diseases International, and their members, and in the lead up to Universal Health Coverage Day (December 12), **the campaign aims to create awareness and ask policy makers to safeguard equity in national UHC strategies and essential health service packages.**

A HISTORICAL COMMITMENT TOWARDS UHC

In September 2019, Member States signed the most comprehensive and ambitious declaration on health in history : The UN Political Declaration on Universal Health Coverage (UHC)

It recognises that UHC is essential to achieve global equity and ensure we 'leave no one behind'. It also emphasises the need to give special attention to the vulnerable and marginalised segments of the population, including the need to strengthen efforts to address rare diseases (Article 34).

In fact, **UHC will not be truly universal unless the needs of persons living with a rare disease are addressed.**

THE CHALLENGE FOR PEOPLE LIVING WITH A RARE DISEASE

The **300** MILLION **PEOPLE** **living with a rare disease around the world and their families face common challenges** in their daily lives as a vulnerable and neglected population.

There are over **6000** RARE DISEASES that are chronic, progressive, degenerative, disabling and frequently life threatening. Due to the rarity of each individual disease and scattered populations, expertise and information is scarce. In health systems designed for common diseases, **rare disease patients face inequities in accessing diagnosis, care and treatments.** This often results in significant social and financial burden on people living with a rare disease.

The **300 million people** living with rare diseases in the world represent a significant group of citizens that need support to be integrated into society and enjoy **THE FULL RESPECT OF THEIR HUMAN RIGHTS.**

KEY STATISTICS ON RARE DISEASES

Affects between 3.5 and 5.9% OF THE POPULATION in the course of their lives.

72 % OF RARE DISEASES ARE GENETIC.

70 % OF GENETIC RARE DISEASES START IN CHILDHOOD

NO CURE for the majority of diseases and few treatments available.

ADDRESSING THE NEEDS OF THE RARE DISEASE POPULATION TO MOVE TOWARDS UNIVERSAL HEALTH COVERAGE

Universal health coverage (UHC) ensures **all people, everywhere, can access the quality essential health services they need without being exposed to financial hardship.**

Member States need to consider three dimensions of coverage when moving toward universal health coverage: in terms of population, in terms of services and in terms of proportion of costs covered.

THE THREE DIMENSIONS OF UNIVERSAL HEALTH COVERAGE

01 POPULATION : More people covered.

02 SERVICES : More services covered (diagnosis, social support, therapies, etc).

03 DIRECT COSTS : Reduced out-of-pocket expenses.

More detailed information on the three dimensions (WHO)

'Reaching the furthest behind first' is recognised as a good strategy to start the process towards UHC. And while countries around the world are at different stages in the development of policies in support of the rare disease community, **any country can today take decisive action to support a greater integration of rare diseases in its UHC model or approach. It is possible to make great progress at a rapid pace even it starting from very little.**

The true benchmark of how inclusive a society can pretend to be is how it addresses the health of its most vulnerable. Policy makers have the opportunity to support the rare disease community in their country by gradually taking a number of actions in each of the three dimensions of UHC.

TAKE ACTION TO ENSURE UNIVERSAL HEALTH COVERAGE IN YOUR COUNTRY OR REGION ADDRESSES THE NEEDS OF PEOPLE LIVING WITH A RARE DISEASE

Recommendations to policy makers.

01 POPULATION

Extend coverage to people living with a rare disease.

Population coverage lags far behind in most countries with a number of hidden, marginalised populations such as people living with a rare disease being left out. Remedying this starts by collecting data to understand the situation and the barriers that are impacting equitable coverage.

Policy makers should :

- Raise awareness and enhance **visibility** of rare diseases in all sectors including health, social, work, education and research.
- Support the **identification** of rare diseases, and their better classification and codification.
- Improve access to accurate and timely **diagnosis** of rare diseases.

02 SERVICES

Include other services and adapt existing ones to the needs of the rare disease population.

People living with a rare disease have more complex needs and some of the services that are essential to them may be different than those of the general population. National authorities need to pay special attention to this when developing their UHC essential health service package in order to include the services that are essential to this vulnerable population.

Policy makers should :

- Facilitate **access** to high quality healthcare and treatments for rare diseases.
- Create policies for the identification, accreditation and support of **experts and expert centres** on rare diseases as well as their national and international networking.
- Identify and establish **social services** relevant to rare diseases and bridge the gap between health and social services.
- Promote **research** on rare diseases to increase the availability of services and treatments for this population.

03 DIRECT COSTS

Protect the rare disease population from further financial hardship.

People living with a rare disease often experience financial difficulties from having to cover out-of-pocket expenses for their care or from paying for treatments. In addition, they have significant additional costs associated with their complex needs, including transport, rehabilitation, and costs linked with lost income from family members who are caregivers. This greater financial burden leads to impoverishment of the rare disease population.

Policy makers should :

- Guarantee **access to affordable treatments** : orphan medicinal products, new medicines and health technologies for rare diseases.
- Ensure people living with a rare disease and disability receive the level of **support** they need.
- Ensure a good work-life balance and **protection from loss of income** for family members who are caregivers.

BRINGING IT ALL UNDER A NATIONAL PLAN FOR RARE DISEASES

Experience from a number of countries (most EU Member States, Australia, Philippines, Japan) has demonstrated that coordinating all these actions under a national plan or strategy for rare diseases is a best-practice. There should be a dedicated funding stream and follow a multidisciplinary approach that mobilises and strengthens the capacities of providers from different sectors. This should be done with the collaboration of national patient organisations who can provide guidance, expertise and real-life evidence coming from patients and their families.

Participate in the #UHC4RareDiseases campaign by posting on social media, meeting with your national patient group and exploring the ways in which you can address the needs of this vulnerable population in your national UHC strategy.

More information at : https://www.rarediseasesinternational.org/uhc4rarediseases

Sources :

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