



National Policy of Rare Diseases

For Prelims: National Policy of Rare Diseases, Pradhan Mantri Jan Arogya Yojana, Rare Diseases, Lysosomal Storage Disorders (LSD), Pompe disease, Cystic fibrosis, Muscular dystrophy, Spina bifida, Haemophilia

For Mains: Initiatives Related to Universal Health Coverage in India.

Why in News?

Recently, a Rajya Sabha Member of Parliament (MP) raised **concerns over [National Policy of Rare Diseases \(NPRD\)](#)** as it did not reach any patient with rare diseases even after several months since its introduction.

What is NPRD?

- **About:**
 - **Ministry of Health and Family Welfare** formulated and launched NPRD in 2021 for the **treatment of rare disease patients**.
- **Aim:**
 - To increase **focus on indigenous research and local production of medicines**.
 - To **lower the cost of treatment** of rare diseases.
 - To **screen and detect rare diseases early at early stages**, which will in turn help in their prevention.
- **Key Provisions of the Policy:**
 - **Categorization:**
 - **Group 1:** Disorders amenable to **one-time curative** treatment.
 - **Group 2:** Those requiring **long term** or **lifelong treatment**.
 - **Group 3:** Diseases for which **definitive treatment is available** but challenges are to make optimal patient selection for benefit, very high cost and lifelong therapy.
 - **Financial Support:**
 - Those who are suffering from rare diseases listed under Group 1 will have the financial support of up to Rs. 20 lakh under the umbrella scheme of **Rashtriya Arogya Nidhi**.
 - Rashtriya Arogya Nidhi provides for **financial assistance to patients, living Below Poverty Line (BPL)** and who are suffering from major life-threatening diseases, **to receive medical treatment at any of the super specialty Government hospitals / institutes**.
 - Beneficiaries for such financial assistance would not be limited to BPL families, but extended to about 40% of the population, who are eligible as per norms of [Pradhan Mantri Jan Arogya Yojana](#), for their treatment in Government tertiary hospitals only.
 - **Alternate Funding:**
 - This includes **voluntary [crowdfunding](#) treatment** by setting up a **digital**

platform for voluntary individual contribution and corporate donors to voluntarily contribute to the treatment cost of patients of rare diseases.

- **Centres of Excellence:**

- The policy aims to strengthen tertiary health care facilities for prevention and treatment of rare diseases through designating eight health facilities as '**Centres of Excellence**' and these will also be **provided one-time financial support of up to Rs. 5 crore** for upgradation of diagnostics facilities.

- **National Registry:**

- A national **hospital-based registry of rare diseases will be created to** ensure adequate data and comprehensive definitions of such diseases are **available for those interested in research and development.**

What are Rare Diseases?

- There are **6,000-8,000 classified rare diseases**, but less than 5% have therapies available to treat them.
- Example: [Lysosomal Storage Disorders \(LSD\)](#), **Pompe disease**, [cystic fibrosis](#), **muscular dystrophy**, **spina bifida**, [haemophilia](#) etc.
- About 95% rare diseases have no approved treatment and less than 1 in 10 patients receive disease-specific treatment.
- 80% of these diseases have **genetic origins**.
- These diseases have differing definitions in various countries and range from those that are **prevalent in 1 in 10,000 of the population to 6 per 10,000**.
- However broadly, a '**rare disease**' is defined as a **health condition of low prevalence that affects a small number of people** when compared with other prevalent diseases in the general population. Many cases of rare diseases may be **serious, chronic and life-threatening**.
- India has close to 50-100 million people affected by rare diseases or disorders, the policy report said almost **80% of these rare condition patients are children** and a leading cause for most of them not reaching adulthood is due to the high morbidity and mortality rates of these life-threatening diseases.

UPSC Civil Services Examination, Previous Year Questions (PYQs)

Prelims

Q. With reference to Ayushman Bharat Digital Mission, consider the following statements: (2022)

1. Private and public hospitals must adopt it.
2. As it aims to achieve universal, health coverage, every citizen of India should be part of it ultimately.
3. It has seamless portability across the country.

Which of the statements given above is/are correct?

- (a) 1 and 2 only
- (b) 3 only
- (c) 1 and 3 only
- (d) 1, 2 and 3

Ans: (d)

Exp:

- Under this mission, citizens will be able to get their Ayushman Bharat health account number,

which can be linked to their digital health records. Ayushman Bharat is a flagship scheme of the country, which was launched as per the recommendation of National Health Policy 2017 to achieve the vision of Universal Health Coverage (UHC). **Hence, statement 2 is correct.**

- It aims to provide digital health IDs to all Indian citizens to help hospitals, insurance firms and citizens access health records electronically when required. It will be provided to every citizen which will also act as their health account. This health account will contain details of each test, each disease, doctor's appointment, medicines taken and diagnosis.
- Health ID is free and voluntary. It will help in analysing health data and ensure better planning, budgeting and implementation of health programmes.
- It is portable, which means the beneficiary can avail treatment in any of the states that have implemented the scheme. **Hence, statement 3 is correct.**
- It leverages capacities available in both public and private sector hospitals, while providing standardised high-quality care, with strong fraud protection mechanisms. **Hence, statement 1 is correct.**
- **Therefore, option (d) is correct.**

Mains

Q. Appropriate local community-level healthcare intervention is a prerequisite to achieve 'Health for All' in India. Explain. **(2018)**

Source: TH

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