Salgaocar Law Review

Volume XI,2025
ISSN 2395-7263

AN INQUIRY INTO THE AYUSHMAN BHARAT PRADHAN MANTRI JAN AROGYA YOJANA IN THE TREATMENT OF RARE DISEASES

*Ammu S

Abstract

India has made significant progress in terms of health, especially in health indicators and infrastructure development. To address health-related disparities in the country, the government has developed progressive policies over the years. Despite significant development over the decades, India's health system is still in its infancy in addressing the challenges posed by rare diseases. Limited government policy and financial support for patients with rare diseases are also significant concerns. This study examines policy synergism between AB-PM-JAY and NPRD, gaps, and challenges faced by patients. It further examines the extent to which the scheme covers rare diseases and how the National Policy can be successfully combined with it. A doctrinal method was used to collect the data for this study. The primary and secondary sources of this study are national policies, national portals, government documents, and journals. Ayushman Bharat has improved access to primary, secondary, and tertiary care for millions of Indians; however, it has not significantly benefited most patients with rare diseases due to policy, financial, and systemic exclusions. The study further recommends dedicated health benefit packages and the use of AB PM-JAY as a Co-Financing Platform.

Keywords: Rare Disease, Health, NPRD 2021, AB PM-JAY, India

Introduction

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ISSN 2395-7263

"Ayushman Bharat programme is India's most definitive step so far towards promotive, preventive, curative, palliative and rehabilitative aspects of Universal Health Coverage (hereafter referred as UHC) ."[1] Ayushman Bharat Pradhan Mantri Jan Arogya Yojana (hereafter referred as AB PM-JAY), aims to provide UHC to over 500 million people by providing financial protection for hospitalization costs. However, the existing framework of AB PM-JAY does not provide adequate coverage for the needs of patients with rare diseases, who face complex and lifelong therapies and high costs. The AB PM-JAY has improved access to secondary and tertiary care for millions of Indians. However, it has not significantly benefited most patients with rare diseases because of the policy's systemic exclusions. Patients with rare diseases individually affect a small population; however, collectively, they affect millions of people in the country.

At present, nearly 300 million individuals worldwide are affected by rare diseases. Persons living in low- and middle-income countries are marginalized and tend to be neglected.[2] Because of its extreme rarity and the lack of awareness about the symptoms of rare diseases by medical practitioners and patients, it is difficult to diagnose accurately at an early stage.[3] The needs of patients with rare diseases are overlooked in the public health system. Such patients require highly specific and lifelong care, including costly diagnostics and orphan drugs.

Research Questions:

1. Does the AB PM-JAY resolve the treatment requirements of patients with rare diseases in conformity with the constitutional safeguards provided to ensure the right to health?

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[1]* Research Scholar, School of Indian Legal Thought, MG University, Kottayam, Kerala, ammuashok0507@gmail.com, 9061924525

Pradeep Kumar Panda, Ayushman Bharat: Challenges and Way Forward, 5 JAIPURIA INT. J. MANAG. RES. 53 (2019).

[2] The Lancet Global Health, The Landscape for Rare Diseases in 2024, 12 LANCET GLOB. HEALTH e341 (2024).

[3] Id.

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2. How can the AB PM-JAY be utilized to strengthen the National Policy for Rare Diseases, 2021, to meet the healthcare needs of patients with rare diseases?
3. What legal and policy reforms are required to ensure the inclusion of rare disease treatment in the AB PM-JAY framework?

The Landscape of Rare Disease in India

Rare diseases do not have a globally agreed-upon definition. It is understood as "a health condition that affects a small number of people compared with other prevalent diseases in the general population."[4] Most rare diseases are genetic and affect early childhood. Rare diseases are degenerative, progressive, life-threatening, and chronic in nature. The World Health Organisation in its Seventy-eighth World Health Assembly recognised "rare disease is often described as a specific health condition affecting 1 in 2000 individuals or fewer in the general population."[5] The regulation of orphan medicinal products in the European Union defines rare diseases as those that affect fewer than 50 per 10,000 European citizens. In contrast, under the American Orphan Drug Act, rare disease conditions are considered to affect fewer population of two lakh individuals in the United States.[6] The definitions vary across countries and regions, depending mainly on the differences in the prevalence rates of rare diseases in each jurisdiction.[7] The landscape of rare diseases is complex and poses challenges in the management and treatment of patients with these diseases. The natural history of rare diseases, availability of treatments, and incentives for drug research and development for these conditions are major concerns.[8]

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[4] Trevor Richter et al., Rare Disease Terminology and Definitions-A Systematic Global Review: Report of the ISPOR Rare Disease Special Interest Group, 18 VALUE HEALTH 906 (2015).
[5] Seventy-Eighth World Health Assembly – Daily Update: 24 May 2025, https://www.who.int/news/item/24-05-2025-seventy-eighth-world-health-assembly---daily-update--24-may-2025 (last visited Aug. 5, 2025).
[6] Claudia Ching Yan Chung et al., Rare Disease Emerging as a Global Public Health Priority, 10 FRONT. PUBLIC HEALTH 1028545 (2022).
[7] Chiuhui Mary Wang et al., Operational Description of Rare Diseases: A Reference to Improve the Recognition and Visibility of Rare Diseases, 19 ORPHANET J. RARE DIS. (2024).
[8] Harsha Karur Rajasimha et al., Organization for Rare Diseases India (ORDI) – Addressing the Challenges and Opportunities for the Indian Rare Diseases' Community, 96 GENET. RES. e009 (2014).

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The scarcity of epidemiological data exacerbates the problems associated with rare diseases in India. The absence of a definition for rare diseases in the country hinders the implementation of evidence-based policies. A standard definition of rare diseases is needed to allow healthcare institutions and governments to respond to the challenges and burdens of rare diseases, thereby considering the needs of patients with rare diseases, their families, and society.[9] The country currently lacks a fully functional and comprehensive national rare disease registry, hampering efforts to develop a definition for rare diseases in India. There are a number of unmet needs in the rare disease patient population, including lengthy diagnostic procedures, lifelong debilitating conditions, inadequate funding, limited and expensive treatment options, and inability to get diagnosed.[10] Furthermore, the burden of rare diseases in India is intensified by socioeconomic inequalities in the healthcare system.

Understanding the National Policy for Rare Diseases 2021

The recognition of rare diseases as an urgent need of the hour around the world has dramatically changed India's attitude towards recognizing the needs of patients with rare diseases. The increasing number of writ petitions in various High courts in India and patient advocacy group initiatives compelled the government to formulate a policy for rare diseases and fulfil its constitutional obligation to protect the right to health for everyone.

India adopted the NPRD 2021, a landmark policy recognizing rare diseases as a public health priority and offering a group-wise classification of rare diseases based on their curability and cost.[11] The NPRD 2021 officially includes **63 rare diseases** in its policies. The primary objective of this policy is to develop a clear framework that will enable the effective management of rare diseases by giving significant attention to the detection, prevention, and

[9] Wang et al., supra note 7.
[10] Chung et al., supra note 6.
[11] Details of National Policy for Rare Diseases, https://www.pib.gov.in/www.pib.gov.in/Pressreleaseshare.aspx?PRID=2043516 (last visited June 16, 2025).

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comprehensive treatment of these conditions. The policy of establishing a Center of Excellence intends to provide advanced treatment options and infrastructural facilities for patients and proposes research and development, treatment support, and institutional coordination.

The government, through the NPRD, provides financial support of ₹50 lakhs per eligible patient through the "Centres of Excellence" and encourages crowdfunding for high-cost chronic therapies.[12] However the policy is trying to address the challenges of rare diseases, it does not adequately taking care about the financial aid needed for long term therapy and the accessibility of the high cost treatments, because most of the rare disease are requiring lifelong treatment with cost up to or more than crores thereby the policy is criticised on its limited operational scope. Furthermore, insufficient integration with other healthcare schemes and the policy's non-binding nature are serious concerns.

Right to Health as a Constitutional Right for Patients with Rare Diseases

The concept of health is multifaceted,[13] and placing health as a right enshrined in Part III of the Constitution provides a strong belief in the values of dignity, equality, and justice for all citizens.[14] The Supreme Court has unequivocally ruled that health is a fundamental right guaranteed under Article 21 of the Indian Constitution, which includes dignity, well-being, healthcare, and access to medical facilities. In its landmark judgment in Pt. Parmanand Katara v. Union of India (1989)[15] has held the protection and preservation of human life and dignity as paramount importance under the Constitution. Similarly, in Paschim Banga Khet Mazdoor

[12] Pragya Chaube et al., Lessons from the Rare Diseases Registry and Analytics Platform Framework for Development of a National Rare Diseases Registry for India, IAS.AC.IN (2038), https://www.ias.ac.in/article/fulltext/jbsc/049/0031.

[13] World Health Org., Human Rights and Health, https://www.who.int/news-room/fact-sheets/detail/human-rights-and-health (last visited Sept. 9, 2025)

[14] Constitution of the World Health Organisation, preamble. and art. 1, July 22, 1946, 14 U.N.T.S. 185.

[15] AIR 1989 SC 2039

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Samity v. State of West Bengal, (1996)[16] the Supreme Court has expanded interpretation of Article 21 and emphasized the state's obligation to provide medical assistance to everyone in a welfare state, and its primary duty is to ensure the well-being of its citizens.

In several judgments, the judiciary has highlighted the role of the state in ensuring and promoting citizens overall well-being. The state must provide quality healthcare services beyond merely offering primary healthcare services. Furthermore, the judiciary has emphasized health as part of social welfare. It facilitates access to medical facilities and ensures effective implementation of health policies and strategies by promoting public health initiatives. Taking proactive measures as a holistic approach in the health system promotes the quality of life of people.

The persistent nature of rare diseases makes patients with rare diseases a vulnerable category that requires the state's urgent attention. Patients with rare diseases are underrepresented in public health discourse. The health policies and schemes of the state inadequately address the needs of patients with rare diseases, which directly affect the right to life under Article 21[17] and equality under Article 14[18] of the Indian Constitution. The directive principles under Article 38[19] obligate the state to promote social welfare and minimize inequalities; Article 41[20] requires the state to provide public assistance in cases of sickness and disability; and Article 47[21] discusses the duty of the state to improve public health. The need to protect the right to health of patients with rare diseases stems from these principles.

The Judicial Approach Towards Patients with Rare Disease

The increased number of writ petitions in Indian courts has addressed issues related to rare diseases and their treatment. Writ petitions in the form of public interest litigation are also

[16] AIR 1996 SC 2426
[17] Https://Www.Legislative.Gov.in/Constitution-of-India, https://www.legislative.gov.in/constitution-of-india (last visited May 30, 2026).
[18] Id.
[19] Id.
[20] Id.
[21] Id.

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increasing, with the majority of these cases concerning the protection of children suffering from life-threatening conditions. Patients, their families, and well-wishers of patients with rare diseases approach the judiciary as a last resort, requiring judicial intervention in state financial assistance for expensive treatments that are unavailable in the public healthcare system.

The High Court of Kerala in Manoj M Mangat House v. State of Kerala[22] and Arif v. The State of Kerala[23] and Others took a similar view regarding the issues faced by patients with rare diseases. The court reiterated access to medical treatment and healthcare, as included in Article 21 of the Indian Constitution. It is held that the government, as a welfare state, has obligations to its people. It is the duty of the state to mobilize resources to ensure the health needs of people by providing quality treatment and healthcare services, even though they are expensive. Lifesaving treatment should not be refused merely because of budgetary constraints.

In Master Arnesh Shaw v. The Union of India & Anr[24] the High Court of Delhi took a similar view to that of the Kerala High Court in the above-mentioned cases. The court held that state resource constraints and financial limitations could not justify the denial of healthcare access. The budget of the financial year 2018 to 2021 was critically examined and analysed by the court, which found that around 193 crores lapsed due to the underutilization of the allocated fund for health. The state's inefficiencies in policy implementation, non-functional crowdfunding platforms, and lack of coordination among stakeholders were discussed. The Union of India was directed to provide support of 50 lakhs per patient with rare diseases and must be granted to all patients with rare diseases (Groups 1, 2, and 3) under the NPRD 2021. Patients who previously denied treatment due to group classification must now be included. This case is now stayed and pending before the Supreme Court of India.

[22] WP(C). No. 21897 of 2016 (J)
[23] 2022 (1) KHC 610, W. P. (C) No. 7984 of 2021
[24] W. P. (C) 5315/2000 & CM APPL. 19189/2020

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The analysis of the judgments reveals systematic neglect of patients with rare diseases in the healthcare sector. The courts generally look into the matters coming before them and address the issue through individualized relief rather than necessitating a systematic reform for a uniform policy guarantee. It is not always advisable to approach the court every time to avail the remedy, as it is a time-consuming process and may not benefit at the time of need.

Ayushman Bharat PM-JAY: An Overview

"Ayushman Bharat is an attempt to move from a sectoral and segmented approach to health service delivery to a comprehensive need-based health care services."[25] The introduction of the AB PM-JAY[26] was a radical policy departure that united central and state resources and defined an expansive beneficiary group. The AB PM-JAY was established as a new standard for large-scale financial protection and is a major welfare initiative aimed at helping economically vulnerable populations in India. India has given special importance to government-sponsored health insurance schemes to improve access to healthcare and safeguard against economic crises. This scheme reflects India's commitment to the UHC and welfare-oriented development. On September 23, 2018[27], India launched the Pradhan Mantri Jan Arogya Yojana under the ambit of Ayushman Bharat, which became the biggest publicly funded health insurance program in the world. This is a crucial step towards achieving India's commitment to UHC as "no one is left behind."[28]

The National Health Authority (NHA) was established as a central agency to manage the scheme throughout the country. It was initially operated by the Ministry of Labour and

[25] Ayushman Bharat - Pradhan Mantri Jan Arogya Yojana, https://www.myscheme.gov.in/schemes/ab-pmjay (last visited July 28, 2026).
[26] Id.
[27] Id.
[28] Aashima, R Sharma - Applied Health Economics and Health Policy & undefined 2024, A Systematic Review of the World's Largest Government Sponsored Health Insurance Scheme for 500 Million Beneficiaries in India: Pradhan Mantri Jan Arogya Yojana, 22 SPRINGER 17 (2024).

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Employment and is currently operated by the Ministry of Health and Family Welfare. Ayushman Bharat is being implemented through two integrated components, namely, primary healthcare in the form of Health and Wellness Centres and secondary and tertiary care through Pradhan Mantri Jan Arogya Yojana.[29] The scheme seeks to provide easy cashless and paperless healthcare services through a publicly funded insurance program, and the scheme cost is shared between the governments. The cost-sharing ratio between the central and some of the northeastern states and the three hilly states is 90:10,[30] and that between the central and all other state governments is 60:40. Approximately 44% of all claims in the framework of the program were associated with medicine, surgery, outpatient diagnosis[31] The operational structure of AB PM-JAY gives the state the flexibility to implement models, including insurance-based systems and trust-based mechanisms. Although it allows state governments to adopt and implement the scheme at the state level, it apparently creates disparities in accessing healthcare services.

AB PM-JAY: The Benefits and Access Mechanisms

The AB PM-JAY scheme provides cashless financial coverage support of up to five lakh rupees per family every year. This improves healthcare accessibility by reducing out-of-pocket expenditures.[32] The scheme covers the comprehensive treatment costs of medical consultation, diagnostics, medicines, surgery, ICU, implants, accommodation, and food of the patient, including the cost of complications arising during treatment. The scheme supports hospital expenses for three days of pre-hospitalization and 15 days of post-hospitalization. An important factor in the scheme as far as disease coverage is

[29] Panda, supra note 1.
[30] Mita Choudhury et al., Ayushman Bharat Pradhan Mantri Jan Arogya Yojana (AB PM-JAY): Design Contours, Emerging Patterns and Cost to the Government, NIPFP.ORG.IN, https://www.nipfp.org.in/media/medialibrary/2024/11/DOC-20241115-WA0002_241126_134556.pdf.
[31] Id.
[32] India.Gov.in | National Portal India: Where Government Information Converges, INDIA.GOV.IN, https://india.gov.in (last visited May 30, 2026).

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concerned, is the support for pre-existing diseases. The scheme covers approximately 1929 medical procedures.[33]

The primary concern of the AB PM-JAY is to address the structural inequalities in the healthcare system faced by the vulnerable Indian population. Individuals who register under the scheme are entitled to its benefits. AB PM-JAY provides healthcare services through public sector hospitals and a selected list of private hospitals as empanelled hospitals under the scheme. AB PM-JAY targets the economically disadvantaged population of the country based on socioeconomic criteria.[34] The effective functioning of AB PM-JAY is limited by practical difficulties in terms of regional disparities, administrative complexities, infrastructural constraints, and lack of awareness among people in India.

These challenges are more complex in patients with rare diseases. Patients with rare diseases require specialized treatment options, such as gene therapies, which are only available in advanced medical institutions, mainly in metropolitan areas and major cities. People from rural and remote areas often face financial difficulties in accessing specialized institutions. The empanelled hospitals under the AB PM-JAY may not always be compatible with the health of patients with rare diseases. In the case of Centers of Excellence under the NPRD 2021, they are mostly designated in the cities and are not sufficient in number, thereby making patients with rare diseases from regions where access to treatment from Center of Excellence is a dream.

AB PM-JAY: Exclusion and the patients Concern

[33] Ayushman Bharat - Pradhan Mantri Jan Arogya Yojana, https://www.myscheme.gov.in/schemes/ab-pmjay (last visited July 28, 2026).
[34] Raghav Dixit, Ambren Chauhan & Khushboo Juneja, Awareness and Utilization of Ayushman Bharat Pradhan Mantri Jan Arogya Yojana (AB-NHPM) among Beneficiaries of Gautam Buddha Nagar District: A Comparative Study, 50 Indian J. Community Med. Off. Publ. Indian Assoc. Prev. Soc. Med. 213 (2025).

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Even without the explicit inclusion of rare diseases under the scheme, certain procedures and treatments related to these diseases may technically fall within the treatment packages offered by AB PM-JAY. The inclusion of patients with rare diseases in the AB PM-JAY scheme remains fragmented and uncertain. This scheme does not address the unique financial and therapeutic realities associated with the treatment of patients with rare diseases. The exclusion of rare diseases can be explicit or implicit in the guidelines. The reimbursement structure of AB PM-JAY excludes specialized treatments, medicines, drugs, and therapies for patients with rare diseases are the explicit exclusions. Implicit exclusions include financial and administrative constraints that prevent equitable healthcare.

The scheme does not explicitly include rare diseases, even as a category of special concern requiring higher financial support and special provisions in its framework. The operational structural exclusions and inclusions of AB PM-JAY are discussed below.

Policy design limitations: The AB PM-JAY health packages are designed to include a limited number of listed essential diagnostics that are beneficial for almost all patients, except those with rare diseases. Enzyme replacement therapy and gene therapy are the most successful treatments for patients with rare diseases. Specialized individualized treatment options are also available for patients with rare diseases in multispecialty hospitals. Unfortunately, these therapies and treatments are highly prohibitive, making them unaffordable for economically disadvantaged people. The AB PM-JAY scheme does not include these treatment modalities. The scheme provides inpatient hospital care but excludes continuous rehabilitation services and patient counseling, which are required by patients with rare diseases in their disease management journey.

Administrative Challenges: The central and state government cooperative cost-sharing structure under the AB PM-JAY reimbursement mechanism creates unequal healthcare access. State governments and their financial stability are crucial for the effective implementation of the AB PM-JAY scheme. Infrastructural developments and the

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institutional efficiency of healthcare institutions vary across states, making healthcare access more complex[35]. The administrative capacity of a state is also essential for implementing such schemes. Patients with rare diseases require advanced diagnostic facilities, genetic laboratories, and trained specialists for their management. Currently, these services are not available under AB PM-JAY. The structural limitations of the scheme exclude these facilities. A state with limited financial and infrastructural resources and administrative capacity cannot implement the scheme in a full-fledged manner, especially for patients with rare diseases.

Financial ceiling: The financial support offered by the scheme is five lakhs of rupees per family, each year. The scheme concerns only a limited number of diseases that can be addressed within its financial cap. The health packages cover a list of diagnostics and treatment options that are commonly useful for all patients, including those with rare diseases, for early management. There is an average five-to-seven-year period taken for detecting a disease as a rare disease, during which time the patients can avail the services offered under the scheme by fulfilling the criteria. Therefore, rare diseases are technically covered by the AB PM-JAY. India's commitment to UHC to provide quality healthcare for all its citizens must succeed only when it includes patients with rare diseases. The insurance coverage offered by the scheme may not be sufficient for patients with rare diseases. Rare diseases are expensive to treat.

No Dedicated Infrastructure: The hospitals empaneled under the scheme cover a list of public and private sector hospitals. These hospitals do not benefit patients with rare diseases because of the nature of the treatments and therapies they require. The national policy offers several dedicated and efficient Designated Centers of Excellence for the treatment of patients with rare diseases. These healthcare institutions are equipped to meet the needs of most patients with rare diseases, although they cannot satisfy all of them. However, these institutions are not empaneled under the AB PM-JAY scheme. Therefore, this scheme does

[35] Ayushman Bharat - Pradhan Mantri Jan Arogya Yojana, supra note 25.

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not benefit patients with rare diseases. The non-recognition of the needs of patients with rare diseases under the AB PM-JAY makes their lives more challenging in terms of availing insurance schemes.

Implications and Future Trajectories

The availability of healthcare resources is scarce in the country, and it is the state's duty to ensure resource allocation among competing social priorities. Therefore, public insurance schemes attempt to balance societal welfare with fiscal responsibility. In the case of rare diseases, the state will always justify limitations in public healthcare schemes based on financial constraints. Article 21 of the Indian Constitution makes the state responsible for preserving the people's lives and dignity. Access to life-saving treatment and medicines cannot be denied merely because of limitations in policy design and financial justification, which raises constitutional concerns regarding the adequacy of state action.

Treating patients with rare diseases intensifies the tension between welfare obligations and financial sustainability. Life-saving therapies for rare diseases often involve extraordinarily high expenditures for a small patient population.[36] Therefore, the state may prioritize cost-effective treatments that benefit larger sections of society. This will affect economically deprived populations of the country, whose medical needs are highly expensive but essential for survival. States have an obligation to ensure their citizens' fundamental rights. The state must ensure the right to access quality healthcare services for all, especially the poor and the vulnerable. As a welfare state, India has an obligation to protect its people under the Constitution of India. The state cannot defend financial resource constraints in terms of people's healthcare. The principle of justice must be applied in the case of resource

[36] Harsha Karur Rajasimha et al., Organization for Rare Diseases India (ORDI)–Addressing the Challenges and Opportunities for the Indian Rare Diseases' Community, CAMBRIDGE.ORG (2014), https://www.cambridge.org/core/journals/genetics-research/article/organization-for-rare-diseases-india-ordi-addressing-the-challenges-and-opportunities-for-the-indian-rare-diseases-community/D18E24DD5B2374F997F3D73841229248.

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allocation, among other state requirements. Equality, justice, and social justice must be the primary objectives of state functions.

Article 14 of the Indian Constitution addresses equality principles and positive discrimination. Discrimination may not always result in explicit classification. This can stem from policies aimed at benefiting all people but resulting in inequalities. The PM-JAY scheme is aimed at benefiting all people who are financially incapable of availing themselves of health services. However, the majority of patients with rare diseases come from low-income families and are not benefitting from India's flagship scheme, which violates the principles of Article 14 of the Indian Constitution. The operational structure of the scheme may appear neutral, as it is compatible with all diseases, but it disadvantages patients with rare diseases. The absence of recognition of the special needs of patients with rare diseases, along with other beneficiaries of the scheme, raises constitutional concerns under Articles 21 and 14 of the Constitution of India.

Towards an Inclusive Care Framework for patients with Rare Diseases

The inadequacy of administrative mechanisms in the healthcare system has resulted in families frequently approaching constitutional courts to seek financial assistance and government intervention to save the lives of patients with rare diseases. Even if the courts provide relief sought by the individual parties, they cannot make comprehensive policy reforms as they lack the institutional capacity to design healthcare schemes and allocate financial and budgetary resources. Moreover, financial resources and awareness of legal and procedural complexity may not be the same for everyone; in this case, those who face difficulties in these areas are unable to approach the courts and remain excluded from relief. Therefore, the repeated necessity for judicial intervention highlights the structural deficiencies within existing healthcare governance. Rights-based healthcare governance requires more predictable and accessible mechanisms rather than discretionary relief.

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A strategic approach to incorporating rare disease care into the framework of the AB PM-JAY program needs to undergo structural reforms to help address the gaps that already exist in the healthcare system and strive to align with the principles of UHC. Patients with rare diseases require a holistic approach in the healthcare system, along with the AB PM-JAY and the National Policy. The following recommendations are made:

The AB PM-JAY scheme must be reframed to include new and advanced treatment options for genetic laboratories, enzyme replacement therapy, and gene therapy for patients with rare diseases that fall under the category of those with effective treatments. The change in the nature of the reimbursement mechanism from a rigid package to a flexible one allows patients with rare diseases to meet the requirements and costs of complex and evolving treatment. The scope of critical outpatient diagnoses must be considered. The formation of a dedicated rare disease fund along with the corporation of the National Policy can achieve all the above discussed suggestions or can be used as a special fund for highly complex cases.

The discussion shows that effective coordination of the National Policy and the AB PM-JAY scheme is required. Digital databases of patients with rare diseases, their treatment protocols, and other records under the National Policy can be made available through the AB PM-JAY scheme. This will help the effective management of patients with rare diseases under the National Policy and AB PM-JAY scheme in terms of tracking the current status of patients and improving policies and strategies according to their healthcare needs. Coordination can integrate the Centers of Excellence under the scheme, which will benefit patients with rare diseases as well as other beneficiaries of the scheme and improve patients' treatment access and lives.

Conclusion

Patients with rare diseases are often considered an important part of India's public health discourse. They are gaining popularity in today's discussions because of the difficulty in solving human rights and fundamental rights issues surrounding patients with rare diseases.

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The medical fraternity has identified new rare diseases in the scientific literature, revealing that the landscape of rare diseases is constantly increasing. Approximately 5000 to 8000 distinct rare diseases have been documented in the medical literature. The existing conditions of India's public health system are not compatible with the issues of rare diseases. There is an urgent need to address the problems of patients with rare diseases. The first step can be taken from India's flagship programme of the AB PM-JAY scheme, which is considered a promising step towards India's constitutional commitment to achieve the right to access quality healthcare services for everyone.

The operational structure of AB PM-JAY is not compatible with the treatment of patients with rare diseases. The health financing support offered by the scheme does not benefit patients with rare diseases. A holistic approach is needed to strengthen the healthcare system to meet the needs of patients with rare diseases. The effective integration of the national health policy with the AB PM-JAY scheme can contribute more healthcare benefits to patients with rare diseases. However, the lack of clear integration between the NPRD and AB PM-JAY leads to fragmented coverage, institutional ambiguity and inconsistent care pathways. Through the coordination between AB PM-JAY and NPRD 2021, India can achieve actual inclusive UHC.