

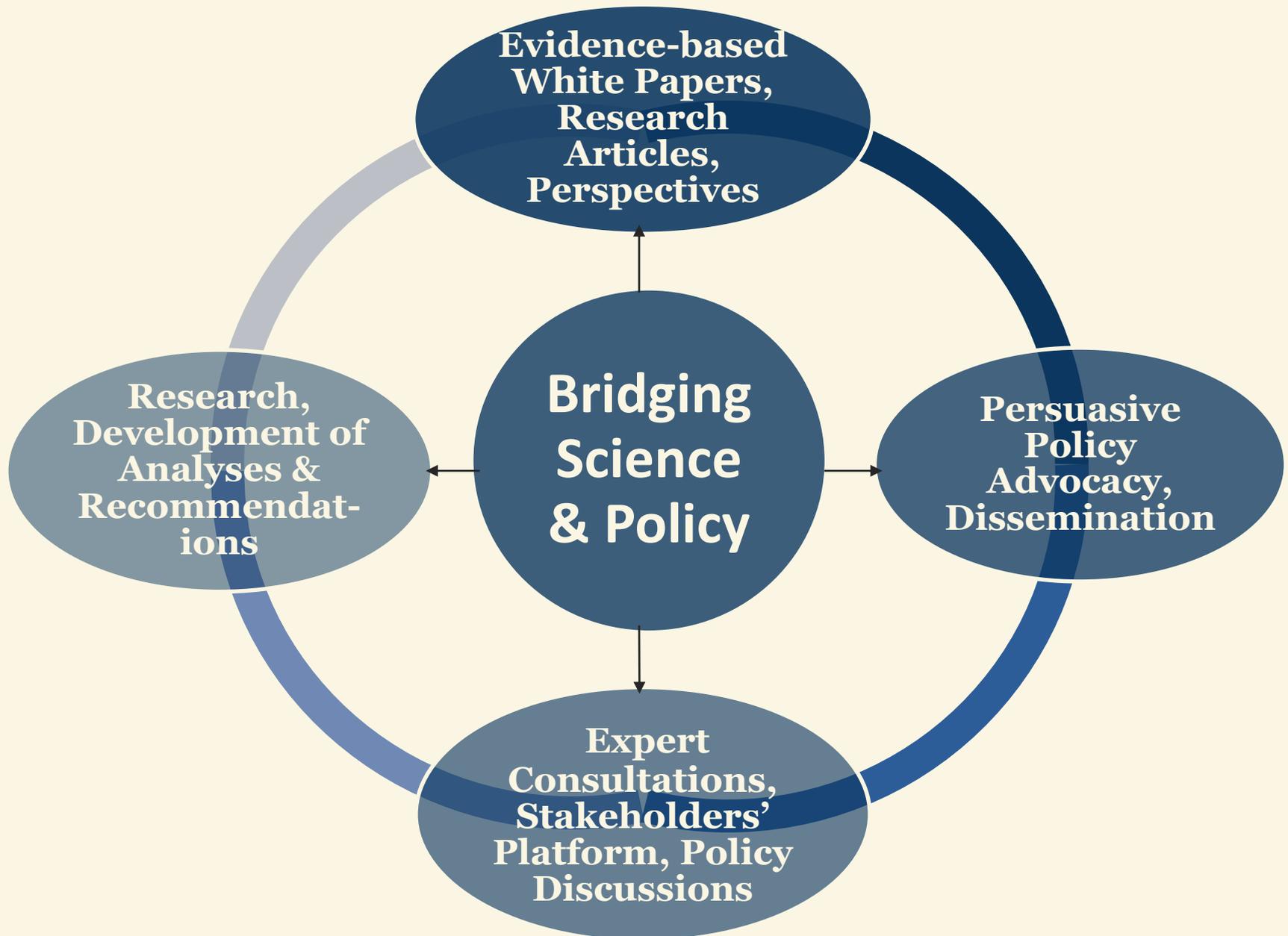


# Science Policy Initiative at Ashoka



ashoka  
UNIVERSITY

# SPI Landscape

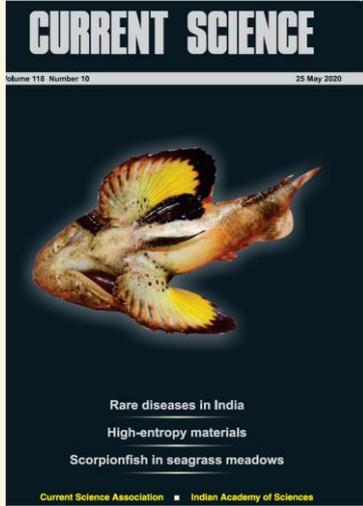




# Vision & Objectives

- Become an effective S&T resource conduit between the government & industry
- Translation of science research, stakeholder consultations and discussions into sound policies through persuasive advocacy
- Foster knowledge exchange on S&T and innovation.
- Promote quality-driven and evidence-based advanced research in S&T
- Strengthen academia – R&D initiatives – industry collaborations
- Further research and higher education in science policy as a subject.
- Strengthen India's global competitive foothold in S&T.

# A Snapshot



**GENERAL ARTICLES**

## Rare diseases in India: time for cure-driven policy initiatives and action

Anjali Taneja\*, L. S. Shashidhara and Alok Bhattacharya

India is estimated to have a large number of patients suffering from rare diseases (RDs). More than 95% of such diseases are incurable. In many cases, the available treatments are expensive and often have to be provided (imported) to the patients, at a cost that adds to the country's socio-economic burden. It is time for India to implement healthcare policies that are focused on encouraging domestic production of drugs against RDs and funding innovative care for them. This article delineates the existing social, economic and policy scenarios governing RDs in India. It also examines some of the global policy approaches in this field. Taking a cue from such international practices, this article advocates the need for a comprehensive regulatory framework for RDs in India with the ultimate goal of ensuring 'cure for all patients'.

**Keywords:** Diagnosis and treatment, health policy initiatives, orphan drugs, rare diseases.

RARE diseases (RDs), in the same spirit, affect a relatively small number of patients worldwide. There is no standard definition of such diseases globally, and differential cut-offs have been used to qualify a disease as rare. For example, in USA, the number of patients need to be fewer than 200,000 in order to be categorized under 'RD'. According to the World Health Organization (WHO), a disease is considered rare if its occurrence is 1 in 100,000 in the population.

In India, the Central Drug Standard Control Organisation (CDSCO)'s definition of RDs is considered as the national standard benchmark. In the new clinical trial guidelines, RD is one that affects fewer than 100,000 persons in the country. About 10% of RDs are genetic disorders and nearly 50% of the patients are children. A large number do not survive beyond the age of 20 (ref. 1). According to various Government of India (GOI) estimates, 15% of deaths take place before the age of 1, 10% between the age of 1 and 5, and 12% between 5 and 15 (ref. 2). Most of these diseases are chronic and degenerative causing extreme disability, which progresses with age. As a result, the patients suffer from RDs often require specialized supportive care.

The demand and patient costs of RDs are high in comparison to other diseases. The high costs are primarily attributed to delayed diagnosis, lack of adequate treat-



**INSIDE**

## Higher Education in India: Securing Quality, Inclusiveness, Innovation through Teachers

Anjali Taneja and L.S. Shashidhara

curiosity, and a drive to work in and contribute towards their respective fields while cherishing a lifetime of open-minded learning.

to bridge the gap between academia and markets and industries in their corresponding field for mutual benefit.

**Objectives**

To nurture an atmosphere where academics remain inspired to learn and teach, and become models to other academics and, above all, to society.

To ensure that the university and its academics mould better students, better citizens and become public intellectuals to lead the society.

To ensure that scholars of the university remain connected with their field and motivated to contribute towards it, in the process helping in the growth of humankind.

**Higher Education in India: Securing Quality, Inclusiveness, Innovation through Teachers**

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It is not just traditional wisdom that teachers or faculty are an enabler of knowledge and wisdom, but it is a fact that we experience in all our life. Thanks to their teachers and faculty who have been instrumental in strengthening a culture of innovative learning and inclusiveness, quality education thrives in countries like the United States of America (USA), United Kingdom (UK), Singapore, Australia and the likes. While in India the knowledge economy is shaping up, a lot still needs to be done, especially in the field of higher education. India continues to grapple with the issue of severe shortage of faculty. Against the rising enrolment rates of students in higher education in India, the number of teachers and faculty employed in education institutions have fallen over the years. Check this out!

According to Government of India's All India Survey on Higher Education (AISHE) of 2019, Gross Enrolment Ratio (GER) in higher education (in the age group of 18-23 years) has increased from 24.3 percent in 2014-15 to 26.3 percent in 2018-19. In absolute numbers, enrolment has increased to 3.74 crore students during the period 2018-19 from 3.42 crore in 2014-15, primarily under Undergraduate

public health, healthcare, higher education, artificial intelligence, blockchain technology, supply chain management, etc





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