

Emerging Policy Landscape of Rare Disease Registries in India: An Analysis in Evolutionary Policy Perspective

Authors : Yadav Shyamjeet Maniram

Abstract : Despite reports of more than seventy million population of India affected by rare diseases, it rarely figured on the agenda of the Indian scientist and policymakers. Hitherto ignored, a fresh initiative is being attempted to establish the first national registry for rare diseases. Though there are registries for rare diseases, established by the clinicians and patient advocacy groups, they are isolated, scattered and lacks information sharing mechanism. It is the first time that there is an effort from the government of India to make an initiative on the rare disease registries, which would be more formal and systemic in nature. Since there is lack of epidemiological evidence for the rare disease in India, it is interesting to note how rare disease policy is being attempted in the vacuum of evidence required for the policy process. The objective of this study is to analyse rare disease registry creation and implementation from the parameters of evolutionary policy perspective in the absence of evidence for the policy process. This study will be exploratory and qualitative in nature, primarily based on the interviews of stakeholders involved in the rare disease registry creation and implementation. Some secondary data will include various documents related to rare disease registry. The expected outcome of this study would be on the role of stakeholders in the generation of evidence for the rare disease registry creation and implementation. This study will also try to capture negotiations and deliberations on the ethical issues in terms of data collection, preservation, and protection.

Keywords : evolutionary policy perspective, evidence for policy, rare disease policy, rare disease in India

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