Rare Disease Network

Life Sciences Innovation Forum

APEC Action Plan on Rare Diseases: Government Checklist Series

APEC Life Sciences Innovation Forum (LSIF) Rare Disease Network

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This checklist maps each of the 30 targets in the APEC Action Plan on Rare Diseases to the government entity best placed to lead its implementation, with collaborating entities noted in the footnotes. Entity titles are indicative only; economies should assign responsibilities according to their own machinery of government. The Action Plan is voluntary and non-binding, and its targets are intended to be pursued in a pragmatic, stepwise manner suited to each economy's context. The corresponding Action Plan target number appears in parentheses after each item.

MINISTRY OF HEALTH

- Create an official definition for rare disease which serves as the basis for regulatory frameworks, policy frameworks, and other policy of relevant local agencies and providers (1.1)[1]
- Establish a transparent process for regularly reviewing the definition of rare disease with input from academia, industry, civil society, non-government organizations and patient groups (1.2)
- Establish some policy and/or program to support the establishment and development of groups to represent rare disease patients and their ability to engage central and local governments (2.1)[2]
- Establish a multi-sectoral advisory committee that includes patients and reports directly to the Health Minister to advise the government on rare disease policy (2.2)
- Allocate time and other resources in public information, education, and communication, including social mobilization and advocacy, to highlight the lives of individuals living with rare diseases and their families (2.3)[3]
- Establish innovative mechanisms to provide seed funding for early-stage and benchtop research on rare diseases and development of orphan products (3.1)[4]
- Conduct an audit of clinical skills needed to address rare disease, identify gaps in the professional workforce, and develop pre-service and in-service training curricula to build capacity (4.1)[5]
- Design and implement multi-professional and multi-disciplinary capacity development programs to raise awareness of rare disease issues among healthcare providers and social workers, and medical, nursing, and other allied health students (4.2)[6]
- Establish programs to develop, support, and utilize underrepresented professionals including genetic counselors, clinical geneticists, rehabilitation therapists, and allied healthcare workers (4.3)[7]
- Establish a regional network to build and share genetic testing and diagnostic infrastructure and capacity that leverages each economy's strengths (5.1)[8]
- Establish newborn screening programs that are fully reimbursable for testable and treatable rare diseases and reviewed every three (3) years (5.2)[9]

[1] In collaboration with the medical product regulatory authority
[2] In collaboration with the agency responsible for civil-society and non-governmental organization registration
[3] In collaboration with the ministry or agency responsible for information and public broadcasting
[4] In collaboration with the ministry or body responsible for science, research, and higher education
[5] In collaboration with the Ministry of Education and the ministry responsible for labour and skills development
[6] In collaboration with the Ministry of Education
[7] In collaboration with the Ministry of Education and relevant professional councils
[8] In collaboration with the Ministry of Foreign Affairs or the economy's APEC focal point
[9] In collaboration with the medical product reimbursement/HTA authority

- Establish domestic referral networks that guide newly-diagnosed individuals to the most appropriate place in the healthcare system to begin treatment and care (5.3)

- Establish Centers of Excellence in meaningful locations given their respective domestic context for comprehensive diagnosis and initial treatment of rare diseases (6.1)

- Establish a clear and efficient process to ensure patients and their families can transition from Centers of Excellence to localized facilities to continue their care (6.2)

- Establish a regional network of Centers of Excellence to share best practices and create an enabling environment for innovation in centralized rare disease care (6.3)[10]

- Achieve consensus on governance and capacity-building measures for managing and storing patient data to optimize scientific discovery, innovation, trust, and societal benefit for rare diseases (9.1)[11]

- Invest in foundational data infrastructure, digital technologies, and capacity-building measures for secure, private, and efficient rare disease patient data capture, storage, and use (9.2)[12]

- Develop and publish non-binding but comprehensive, whole-of-government, and medium- to long-term plans for addressing rare diseases domestically (10.1)

- Enact enforceable, comprehensive legislation, policy, or mechanism at least covering provisions on the research, diagnosis, and treatment of rare diseases (10.3)[13]

MEDICAL PRODUCT REGULATORY AUTHORITY

- Establish policies and fit-for-purpose protocols for orphan product assessment, including international alignment and expedited registration pathways (1.3)

- Streamline processes for research and clinical trial design, method, and ethics approvals in consultation with industry and patient organizations (3.3)

- Establish regulatory mechanisms with input from orphan product developers to ensure efficient review, approval, and access of new products for patients (7.1)

MEDICAL PRODUCT REIMBURSEMENT/HTA AUTHORITIES

- Establish pricing mechanisms with input from the biopharmaceutical industry to make orphan products more available, accessible, and affordable to patients (7.2)

- Establish a reimbursement structure with input from industry to make funding decisions for orphan products more transparent and effective for payers and patients (7.3)

[10] In collaboration with the Ministry of Foreign Affairs or the economy's APEC focal point
[11] In collaboration with the data protection authority
[12] In collaboration with the data protection authority and the ministry responsible for digital or information and communications technology
[13] In collaboration with the relevant legislative committees

MINISTRY OF FINANCE

- Establish financial and in-kind incentives to encourage and support commercialization of domestic rare disease research and development of orphan products (3.2)[14]

MINISTRY OF SOCIAL DEVELOPMENT / SOCIAL WELFARE

- Establish policies and programs to better connect health systems with social welfare or assistance systems for patients and families to attain a minimum standard of living (8.1)[15]

- Establish policies and programs to provide some level of publicly funded social insurance in tandem with private social insurance to mitigate risks for patients and families (8.2)[16]

- Implement adjustments to employment and education systems in collaboration across departments or ministries to improve inclusivity and accommodation for individuals living with a rare disease (8.3)[17]

- Integrate legislative provisions for rare diseases into other areas of legislation outside healthcare such as social security, disability, employment, and housing (10.2)[18]

DATA PROTECTION / DIGITAL GOVERNANCE AUTHORITY

- Facilitate cross-border data flows while respecting data privacy and applicable domestic laws and regulations (9.3)[19]

[14] In collaboration with the ministry responsible for trade, industry, or economic affairs
[15] In collaboration with the Ministry of Health
[16] In collaboration with the Ministry of Health and the Ministry of Finance
[17] In collaboration with the ministry responsible for labour and employment and the Ministry of Education
[18] In collaboration with the relevant legislative committees and the ministries responsible for housing and labour
[19] In collaboration with the Ministry of Health and the Ministry of Foreign Affairs or the ministry responsible for trade