



MALAYSIAN RARE DISEASE LIST

National Rare Disease Committee

Ministry of Health Malaysia

Malaysian Rare Disease List

Definition:

Rare disease is defined as a life-threatening and/or chronically debilitating rare condition as listed in the Malaysian Rare Disease List.

The criteria for inclusion a disease in the Malaysian Rare Disease List are :-

1. There are confirmed patients in Malaysia
2. The disease affects fewer than 1 in 4,000 people in Malaysia*
3. The disease is a severe condition
4. Its inclusion is approved by the national advisory committee**

* Based on expert opinions and on local epidemiologic data when available

** National Rare Disease Committee (Jawatankuasa Penyakit Jarang Jumpa Kebangsaan, Kementerian Kesihatan Malaysia)

Note: The availability of treatment or intervention should also be considered to decide if a disease should be listed. However it is not a mandatory criteria.

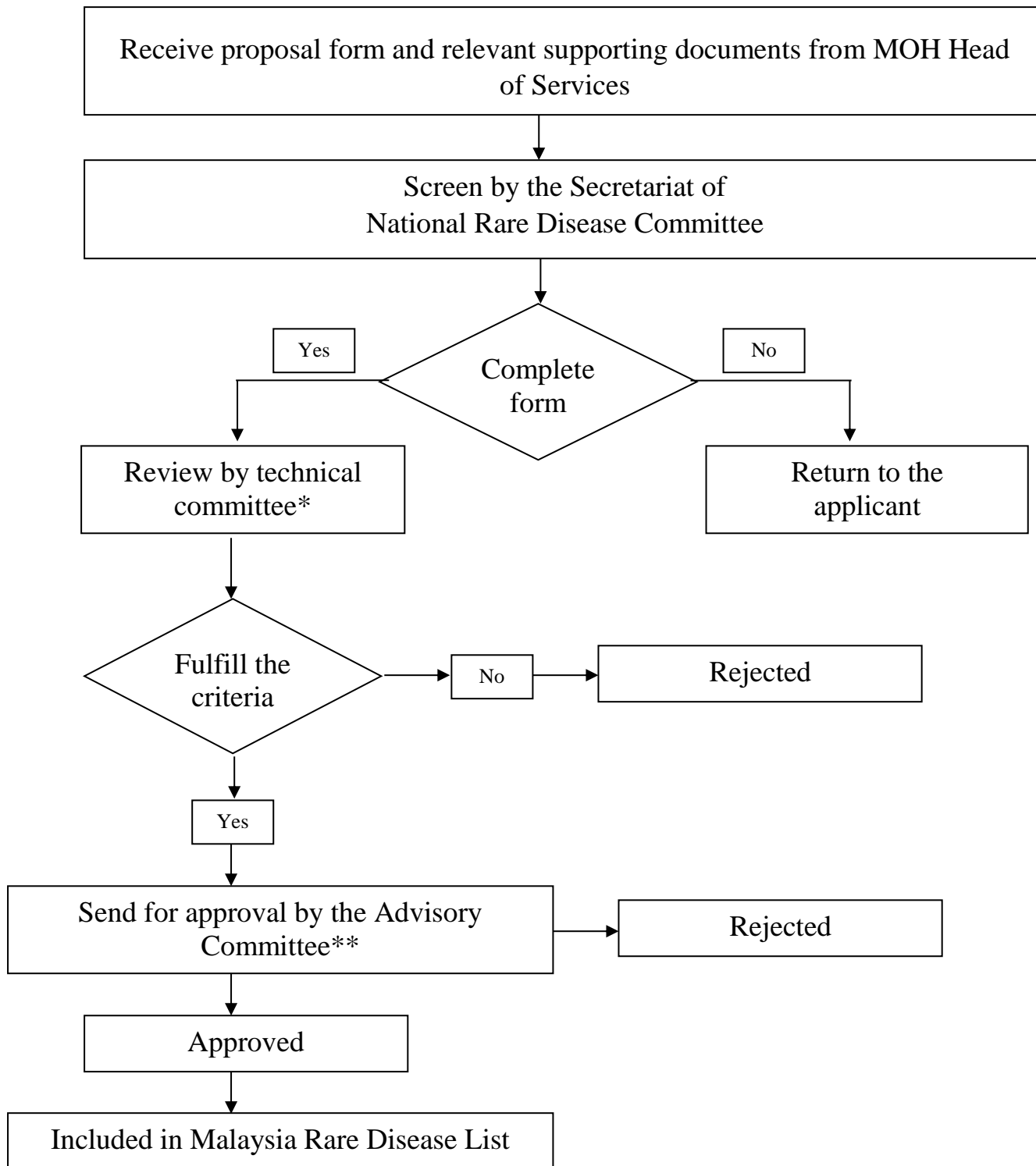
The purpose of having the list are :-

1. To support the policy planning and development of a holistic management of rare diseases in Malaysia under National Framework for Rare Disease in Malaysia
2. To facilitate and harmonization in the designation and registration of orphan drugs

The list will be revised periodically to keep the list current and in line with newly acquired knowledge, real-world evidence, and new treatment options. The list can be downloaded via :-

<https://www.pharmacy.gov.my/v2/en/documents/malaysian-orphan-medicines-guideline-2020.html>

Application procedure to include a new disease in the Malaysian Rare Diseases List



*Working Committee on Clinical management & Supportive Care (Jawatankuasa Kerja Pengurusan Klinikal & Sokongan)

**National Rare Disease Committee (Jawatankuasa Penyakit Jarang Jumpa Kebangsaan)

Proposal form format

Date:

To:

Chairman
National Rare Disease Committee
Ministry of Health, Malaysia
Att : Deputy Director General of Health (Medical)

I would like to propose that.....(*disease name*)..... to be included in the Malaysian Rare Disease List based on the following justifications:

1. There are confirmed patients in Malaysia
.....(*please provide supporting data or documents*)
2. The disease affects fewer than 1 in 4,000 people in Malaysia*
.....(*please provide supporting data or documents*).....
3. The disease is a severe condition
.....(*please provide supporting data or documents*).....

Thank you

Yours sincerely,

Name of the proposer:(*must be a registered medical practitioner*)....

Affiliation:.....

Official stamp:

MOH Head of Services

Basic Specialty :-	Medical Subspecialty :-	Surgical Subspecialty :-
<ol style="list-style-type: none"> 1. Anaesthesiology 2. Forensic 3. Neurosurgery 4. Obstetrics & Gynaecology 5. Ophthalmology 6. Orthopaedic 7. Otorhinolaryngology 8. Pathology 9. Paediatric 10. General Medicine 11. Emergency Medicine 12. Nuclear Medicine 13. Rehabilitation Medicine 14. Sports Medicine 15. Transfusion Medicine 16. Psychiatry 17. Radiology 18. Radiotherapy & Oncology 19. General Surgery 20. Paediatric Surgery 	<ol style="list-style-type: none"> 1. Cardiothoracic Anaesthesiology and Perfusion 2. Dermatology 3. Endocrinology 4. Gastroenterology & Hepatology 5. Geriatric 6. Haematology 7. Infectious Diseases 8. Cardiology 9. Nephrology 10. Neurology 11. Palliative 12. Respiratory 13. Rheumatology 	<ol style="list-style-type: none"> 1. Breast & Endocrine Surgery 2. Hepatobiliary 3. Cardiothoracic Surgery 4. Colorectal Surgery 5. Plastic & Reconstructive Surgery 6. Thoracic Surgery 7. Upper Gastrointestinal Surgery 8. Urology Surgery 9. Vascular Surgery 10. Burn & Trauma Surgery