

### Main points from policymakers consultation

Representatives from:

- Pharmaceutical Division, Ministry of Health
- Finance Division, Ministry of Health
- Medical Development Division, Ministry of Health
- Ministry of Women, Family and Community Development

Topic	Points of discussion
Committee for rare disease	<ul style="list-style-type: none"><li>● MOH has formed a committee for rare diseases.</li><li>● Under this committee there are 3 subcommittee</li><li>● The committee was recently endorsed by MOH Director General and letter of appointments have been sent out to members of the committee</li><li>● Plan of action next is to have a meeting to discuss how to implement strategies in regards to the recommendation by IDEAS and the team.</li><li>● The committee will consist of different stakeholders: clinicians HKL, UMSC and others as well as associations such as MOPI, PhAMA and MEPs</li><li>● Some of the roles &amp; objectives of the committee include:<ul style="list-style-type: none"><li>○ Management &amp; governance regarding the services for rare diseases.</li><li>○ Strengthen the laboratory services and data collection</li><li>○ Governance - MOH will decide on the direction in managing the clinical aspect and also the laboratory aspect in rare disease management.</li><li>○ They will also monitor, supervise and coordinate guidelines, policy and procedures regarding the management of rare diseases as decided by MOH.</li><li>○ There is a need to decide on the direction in managing the clinical aspect – monitoring and evaluation.</li><li>○ To come up with a clinical practical guideline and review it when necessary.</li><li>○ Strengthen laboratory services – whatever services we have they are looking to expand and redistribute across the nation.</li><li>○ Technical unit of the committee will advise on how to prioritise patients &amp; treatments.</li><li>○ Governance - MOH will decide on the direction in managing the clinical aspect and also the laboratory aspect in rare disease management.</li><li>○ Committee will also address how to manage orphan drugs in the current Malaysian market.</li></ul></li><li>● MOH is coming up with a list for rare disease and will decide on the criteria on how they want to include the list.</li></ul>

	<ul style="list-style-type: none"> <li>● They will come up with a policy and mechanism to list these diseases to have the empowerment to include, extract and make some amendments to the list of rare diseases and decide whether it will be done by ratio or it will all be listed down as practiced by Taiwan.</li> <li>● MOH is aware of the trend of new drugs being approved every year. These things are taken into account and every year there will be new funding.</li> <li>● Screening of disease will come under strengthening of lab services</li> </ul>
Funding	<ul style="list-style-type: none"> <li>● In regards to other RDs there are funding mechanism that could be explored through tabung amanah but this depends on the priority on workload.</li> <li>● There is a need to speak to insurance companies. If a disease is included in the list of RDs will it impact patients' abilities to obtain insurance? – important to consider this</li> <li>● Need to speak to industry in regards to lowering prices - If there are mechanisms to do so</li> <li>● ministry hospitals, university hospitals &amp; hospital under ministry of defence are doing pooled procurement for the Southeast Asia region to have better bargaining power.</li> </ul>
Suggestions for White Paper	<ul style="list-style-type: none"> <li>● Important to include Ministry of Education in the discussion and potentially in the committee.</li> <li>● The rehabilitation issue involves MOH, and MOW and MOE. The component of rehabilitative and palliative care needs to cut across these ministries.</li> <li>● MOW is conducting research on the caregivers of people with disabilities.</li> <li>● For the functionality of the paper it is important to structure it in a way that outlines the social aspects of rare diseases.</li> <li>● The paper needs to outline the parts that different ministries are responsible for.</li> <li>● There is a need to involve JPA and HRDF, however due to the reduction of civil servants there will need to be a strong justification for creating positions for genetic counsellors.</li> <li>● Public health involvement in this will be through maternal and child health – implementation of folic acid in food</li> <li>● Request some recommendations from HRDF especially due to the 1% reduction every year for the next five years.</li> </ul>
General Rare Disease	<ul style="list-style-type: none"> <li>● Considering implementing MCDA to determine how to prioritise specific diseases or treatment.</li> <li>● Treatment should be made available to people in Sabah and Sarawak. Most treatments are currently concentrated in KL, Penang &amp; Johor- associated travel costs to receive treatment is high.</li> <li>● Need to involve other ministries into this discussion to address their relevant responsibilities.</li> </ul>

