

### Main points from Industry consultation

Participated by representatives from:

- Sanofi
- PhAMA

Topic	Points of discussion
White paper draft	<ul style="list-style-type: none"><li>● Put the paper in the language of policymakers</li><li>● How do we put together high level and on-the-ground changes, but maintaining that kind of language of policymakers.</li><li>● Policymakers – “how am I going to accomplish it in x number of years”</li><li>● How are we able to provide input in a practical and digestible way that does not scare the government away with thousands of diseases</li></ul>
APEC	<ul style="list-style-type: none"><li>● The APEC paper was put together after consultation – all the countries were encouraged to go back based on the current status and forming a national rare disease committee is one of the goals</li><li>● Next year Malaysia is hosting the APEC, and all the countries will meet to see how countries have progressed and learn from each other</li><li>● It is a work-in-progress, no timeline was provided, but they have indicated that it is multi-stakeholder engagement</li><li>● The UN are working towards putting RD into a political agenda – there is a top-down pressure for governments. Thailand are taking the lead. We have the opportunity, especially with the APEC, the work that Malaysia is working on now then we can put it on a higher priority</li><li>● Sanofi was part of the working group</li><li>● APEC is at a higher level and countries are supposed to implement it on their own</li><li>● For Malaysia, we came back from the APEC and did nothing</li><li>● Thailand took the opportunity to support the recommendations. Thailand also driving at the UN level and secured the RD APEC Forum in Thailand.</li><li>● The project is funded by APEC Life Science Council</li><li>● Three years down the road, the awareness is greater.</li><li>● This year is supported by 5 companies</li></ul>
Role of industry	<ul style="list-style-type: none"><li>● Sanofi patient assistance schemes is a bridging program done till a patient has access to another funding. It is a process done through consultation with governments, patient economic condition, physicians</li><li>● Sanofi noted that they provide non drug related support as well.</li></ul>

Role of policymakers	<ul style="list-style-type: none"><li>● Government cannot sustain the entirety of RD funding and there is a problem of lack of donations to the societies and NGOs and that industry needs to discuss how they could allocate their funding</li><li>● In relation to approaching policymakers, Sanofi expressed that the government has been quite receptive and open to honest discussions. For Rare diseases, important policymakers to speak to include medical development department. Public health department non committal towards rare disease as their main focus are on other NCDs.</li><li>● Discussed the possibility/need for a local pharmaceutical industry and investment in this industry in Malaysia. Sanofi noted that it is difficult to have this as it still does not guarantee access to market.</li><li>● Discussed the importance of speaking to the ministers and policymakers to make progress in rare disease.</li><li>● Recent (last month) town hall with the minister and rare disease was mentioned – alluding to funding – MOH coming up with national rare disease committee to come up with a rare disease definition.</li></ul>
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