



# Asia Pacific Alliance of Rare Disease Organisations

## MANAGING RARE DISEASES IN APAC DURING COVID-19 ORGANISATIONAL CHALLENGES, RESPONSES, AND FUTURE DIRECTION



Brought to you by:

ASIA PACIFIC ALLIANCE OF RARE DISEASE ORGANISATIONS

In partnership with

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The Asia Pacific Alliance of Rare Disease Organisations highlights the main findings from the first study on the impact of Covid-19 on the functioning of rare disease organisations in the Asia Pacific. The objective was to understand the impact of the pandemic on rare disease organisations and patients, organisational challenges in delivering support to members, and explore opportunities for improvement in preparedness level for both patients and patient organisations in the future.

### Methodology

- Online survey distributed to rare disease organisations in the Asia Pacific region (organisations grouped by similarities in healthcare systems and socio-economic status)
- Follow up forum to corroborate and confirm conclusions
- Quantitative and qualitative data analysis

### PARTICIPATING ORGANISATIONS

Total of **80 valid responses** across  
**10 different regions**



Region	Number of organisation
Australia	15
China mainland	30
Hong Kong	18
India	2
Japan	2
Malaysia	3
New Zealand	1
Philippines	1
Singapore	2
Taiwan	3
Unknown	3
<b>Total</b>	<b>80</b>



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The results are based on an online survey carried out by APARDO in English and Mandarin in May 2020. A total of 80 responses came from patient organisations in 10 countries. Findings were corroborated in a follow-up forum.

## 1. Covid-19 Impact on Rare Disease Organisations and Patients

The cessation of non-urgent healthcare services and interruption of supply chains have had an unprecedented and catastrophic impact on patients who rely on the largely volunteer run rare disease organisations. In particular, the study finds compromised delivery of support services and increased workloads. Findings illustrate that:

**7**  
out of  
**10**



7 out of 10 or more organisations

- Faced decreased funding and staffing; were forced to cancel events and activities;
- Struggled to support patients and/or needed to change their mode of operation/digitalise support activities
- Were unable to access patients
- Faced increased workloads due to requirement to coordinate care for patients who were unable to access the routine channels of care

**6**  
in  
**10**



More than 6 in 10 organisations

- Functioned at lower capacity/became non-functional
- Experienced reduced supply of medication and reduced funding

**5**  
out of  
**10**



More than 5 out of 10 organisations highlighted increased need for psychological health support.

**9**  
out of  
**10**



9 out of 10 organisations

- Used digital tools and social media for alternate modes of communication with patients
- Employed various modes of tele-medicine to convey guidance and information from professionals

### Other challenges of a similar or larger magnitude include:

- Discontinuation of hospital services and rehabilitation programs
- Deterioration of mental health from social isolation
- Hurdles in access to personal protective equipment
- Patient unfamiliarity and discomfort with digital platforms

- Lack of accurate and reliable information on C-19

Clearly, the pandemic has exacerbated existing challenges of organisations in supporting patients with rare diseases and further magnified the obstacles of access to healthcare and social support.

At the same time, the survey also highlighted a [silver lining](#).

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### More than 5 out of 10 organisations

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- ⊕ Were able to adapt and digitise their operations
- ⊕ Improved their relationships with and found support from alternative rare disease organisations
- ⊕ Were able to coordinate and access PPE supplies among rare disease organisations and members

The adaptability of organisations in managing to pivot to the changing landscape and digitise their operations and increase the sharing of information and resources with partner organisations indicates their resilience and creativity. It also constitutes an alternate and sustainable model of healthcare for patient populations in the region.

## 2. Recommendations

In order to facilitate enhanced preparedness levels and continuation of the critical services that rare disease organisations deliver, APARDO strongly recommends these focus areas:

- Urgent mental health support (in accessible forms) for rare disease patients
- Funding of special projects that can support resilience and preparedness
- Advocacy training for improved capacity within patient organisations
- Facilitating access to reliable sources of information and expertise among rare disease organisations

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