

**Additional File 2.** Top three areas of impact of COVID-19 on rare disease patients from each jurisdiction group

|   | Most frequently identified                        | 2 <sup>nd</sup> most frequently identified         | 3 <sup>rd</sup> most frequently identified        | Least frequently identified              |
|---|---|--|---|--|
| <b>Overall (n=189)*</b>                     | Reduced access to healthcare (n=81; 43%)          | Patient's daily living and social life (n=49; 26%) | Patient's physical health (n=27; 14%)             | Financial impact (n=12; 6%)              |
| <b>HKSAR, China (n=42)*</b>                 | Reduced access to healthcare (n=19; 45%)          | Patient's daily living and social life (n=13; 31%) | Patient's physical health (n=6; 14%)              | Financial impact (n=0; 0%)               |
| <b>Mainland China (n=65)*</b>               | Reduced access to healthcare (n=32; 49%)          | Patient's daily living and social life (n=14; 22%) | Patient's physical health (n=10; 15%)             | Patient's psychological health (n=3; 5%) |
| <b>Australia, New Zealand (n=49)*</b>       | Reduced access to healthcare (n=17; 49%)          | Patient's psychological health (n=12; 24%)         | Patient's daily living and social life (n=9; 18%) | Financial impact (n=4; 8%)               |
| <b>Japan, Singapore, Taiwan (n=14)*</b>     | Patient's daily living and social life (n=6; 43%) | Reduced access to healthcare (n=4; 29%)            | Financial impact (n=2; 14%)                       | Patient's psychological health (n=0; 0%) |
|   |   |  | Patient's physical health (n=2; 14%)              |  |
| <b>India, Malaysia, Philippines (n=16)*</b> | Reduced access to healthcare (n=5; 31%)           | Patient's psychological health (n=4; 25%)          | Patient's physical health (n=2; 13%)              | Financial impact (n=0; 0%)               |
|   | Patient's daily living and social life (n=5; 31%) |  |   |  |

|                           |                        |               |                      |                  |
|---------------------------|------------------------|---------------|----------------------|------------------|
| Reduced healthcare access | Physical health impact | Social impact | Psychological impact | Financial impact |
|---------------------------|------------------------|---------------|----------------------|------------------|

\* Participants could list up to 3 areas of patient impact

**COVID-19** coronavirus disease of 2019; **HKSAR** Hong Kong Special Administrative Region