

Additional File 1. Top three areas of concern on the impact of COVID-19 on organisations from each jurisdiction group

| | Most frequently identified | 2 nd most frequently identified | 3 rd most frequently identified | Least frequently identified |
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| Overall (n=177)* | Patients' physical and psychological support (n=59; 33%) | Daily operation of organisation (n=40; 23%) | Preparedness for COVID-19 (n=22; 12%) Decreased funding to organisation (n=22; 12%) | Economic impact on patients (n=8; 5%) |
| HKSAR, China (n=41)* | Patients' physical and psychological support (n=12; 29%) Preparedness for COVID-19 (n=12; 29%) | Daily operation of organisation (n=7; 17%) | Decreased funding to organisation (n=4; 10%) Perception of COVID-19 (n=4; 10%) | Economic impact on patients (n=1; 2%) Reduced awareness on rare diseases (n=1; 2%) |
| Mainland China (n=55)* | Patients' physical and psychological support (n=23; 42%) | Daily operation of organisation (n=14; 25%) | Economic impact on patients (n=5; 9%) | Perception of COVID-19 (n=2; 4%) |
| Australia, New Zealand (n=43)* | Patients' physical and psychological support (n=13; 30%) | Daily operation of organisation (n=11; 26%) | Decreased funding to organisation (n=8; 19%) | Preparedness for COVID-19 (n=0; 0%) |
| Japan, Singapore, Taiwan (n=18)* | Decreased funding to organisation (n=5; 28%) | Patients' physical and psychological support (n=4; 22%) Daily operation of organisation (n=4; 22%) Preparedness for COVID-19 (n=4; 22%) | Reduced awareness on rare diseases (n=1; 6%) | Economic impact on patients (n=0; 0%) Perception of COVID-19 (n=0; 0%) |
| India, Malaysia, Philippines (n=14)* | Daily operation of organisation (n=4; 29%) | Perception of COVID-19 (n=3; 21%) | Patients' physical and psychological support (n=2; 14%) Decreased funding to organisation (n=2; 14%) Preparedness for COVID-19 (n=2; 14%) | Economic impact on patients (n=0; 0%) |

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| Impact on organisation | Patient's well-being | COVID-related aspect | Awareness on rare diseases |
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* Participants could list up to 3 areas of concern

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