



Government of **Western Australia**  
Department of **Health**

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Ms Nicole Millis  
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Via email: [nicole.millis@rarevoices.com.au](mailto:nicole.millis@rarevoices.com.au)

Dear Ms Millis

**PRIORITY COVID-19 TESTING FOR PEOPLE LIVING WITH A RARE DISEASE; and COVID-19 PANDEMIC: CRITICAL CARE GUIDELINES FOR AUSTRALIANS LIVING WITH RARE DISEASES.**

Thank you for your letters dated 23 March and 8 April 2020. I appreciate you highlighting the concerns of people in the rare disease community around the availability and turnaround time of testing for Novel Coronavirus 2019 (COVID-19), and the need for critical care guidelines.

The Western Australian Department of Health (WADOH) is working alongside the Australian Government to ensure the best possible health care is provided to all Western Australians during the COVID-19 pandemic. The WADOH is also working closely with the WA Department of Communities to develop targeted clinical, public and communications actions, particularly for vulnerable groups.

Early in the pandemic response, the WADOH recognised vulnerable populations (including those living with a rare disease) as priority groups requiring attention and specific consideration. As such, a dedicated “vulnerable groups” workstream was developed and it has valuably contributed to our pandemic planning and response efforts. This workstream is comprised of multiple clinical working groups with first-hand experience of treating and caring for people living with rare diseases. These groups (e.g. neurological, immunological, cardiovascular, renal, respiratory), have been facilitated by policy makers with strong expertise in rare diseases.

The working groups have identified clinical issues and emerging risks surrounding the provision of usual standards of care during the COVID-19 pandemic. Moreover, they have determined enablers and mitigation strategies to address identified issues and risks. A heightened emphasis has been placed on ensuring discussions and preparation of goals of care with patients, their families, and their health care providers. This aligns strongly with the person-centred approach to health care delivery outlined as a priority in WA’s Sustainable Health Review.

The clinical working groups have been developing COVID-19 clinical care guidelines and patient information sheets to ensure the health care needs of Western Australians, particularly vulnerable populations, continue to be met during this time. Where appropriate, community reference groups have been consulted in the development of these documents. Additionally, letters of support have been prepared for people with pre-existing conditions (or their carers), to ensure flexible work and study arrangements and/or travel across regional boundaries for medical appointments.

Multiple aspects of clinical redesign have occurred across clinical specialities to minimise the risk of infection to vulnerable populations (e.g. expansion of telehealth services), and to safeguard the availability of a highly specialised (and often relatively small) workforce for these groups of patients. Along with clinical specialists, the WADOH has been striving to ensure a continued supply of medicines and related equipment for people who require them on a regular basis. The WADOH is also regularly reviewing international evidence regarding the effects of the COVID-19 pandemic, including the best management of patients with co-morbidities.

The WA COVID-19 testing protocols are in line with the National Guidelines for Public Health Units released by the Communicable Disease Network Australia. Currently in WA there are multiple COVID-19 clinics across metropolitan and regional areas, and in addition, numerous private pathology collection centres. In other regional areas people can go to a public hospital, health service or remote health clinic. The testing criteria in WA has been expanded to include anyone with a fever of 38°C or above, OR a documented history of a fever in the last few days OR an acute respiratory infection (e.g. shortness of breath, cough, sore throat).

Meticulous preparations for emergency and intensive care (ICU) surges in WA due to COVID-19 have occurred, including the procurement of a significant number of additional ventilators to enable a large increase in the number of suitable ICU beds. An ICU decision-making framework has also been developed, underpinned by the ethical principles of utilitarianism and distributive justice. The framework is supported by a committee of broad membership (including an ethicist, and consumer and religious representatives), to facilitate equitable decisions being made in the event of resource allocation constraints.

I understand your concerns for people living with a rare disease and assure you that the WADOH is working tirelessly to appropriately support people living with rare diseases through the COVID-19 pandemic, and to protect them from experiencing adverse outcomes.

Yours sincerely



Dr Andrew Robertson  
**CHIEF HEALTH OFFICER**

30 April 2019