Protecting the rare during a rare pandemic

To the Editor: The great complexity and unmet need in rare diseases is highly challenging for the estimated two million Australians with a rare disease.[1] The coronavirus disease 2019 (COVID-19) pandemic has created enormous health, social and economic burdens, exacerbating the challenges and uncertainty facing people with severe, chronic and often disabling rare disease. Systemic, nuanced, flexible and coordinated responses are required.

The vulnerability of rare disease patients is evidenced by the preliminary results of a global survey of over 5000 mostly European rare disease patients,[2] which found that nine out of ten patients are experiencing interrupted care because of COVID-19. Issues include frequent cancellation or postponement of surgeries and transplants, allied health and primary care or specialist appointments, and interrupted psychiatric care. There are reports of losing access to in-home and hospital therapies and diagnostics, and of closures of hospitals and units that provide ongoing rare disease care. Over half of respondents with access to follow-up care through hospitals chose not to attend in fear of contracting COVID-19. Despite a relatively smaller Australian COVID-19 burden, these sentiments are echoed locally.

The Australian National Strategic Action Plan for Rare Diseases[1] has three pillars: awareness and education; care and support; and research and data. This policy framework underpins rational, evidence-based and evolving responses for Australians with a rare disease. The peak body, Rare Voices Australia, drew on the Action Plan to formulate a statement[3] outlining measures to ensure the rare disease community is protected and considered in the national COVID-19 response. Issues addressed in the statement include triage; clinical care guidelines informed by rare disease experts; continuity and coordination of care; stricter isolation and enhanced testing; and increased utilisation of digital health, including virtual clinics and telemedicine. Subsequently, Rare Voices Australia also called for governments to exercise flexibility around school attendance for rare disease families.

Positively, the European survey[2] revealed increased participation in telemedicine, with a high degree of satisfaction. Australian rare disease specialist clinics have historically provided care over vast distances. Australia's transition to telehealth therefore provides an opportunity to connect with families, particularly those with huge disease burden, within their community. This may enable transition to more person-centred health care, a foundation principle of the Action Plan.

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Competing interests: Nicole Millis is the CEO of Rare Voices Australia. ■

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References are available online.

1 Australian Government Department of Health. National Strategic Action Plan for Rare Diseases. Canberra: Australian Government, 2020. https://www.health.gov.au/resources/publications/national-strategic-action-plan-for-rare-diseases (viewed May 2020).

2 Eurordis. 9 in 10 people living with a rare disease experiencing interruption in care because of COVID-19 [press release]. Paris: Eurordis, 2020 http://download2.eurordis.org/documents/pdf/PressRelease_COVID19surveyresults.pdf (viewed May 2020).

3 Rare Voices Australia. COVID-19 pandemic: critical care guidelines for Australians living with a rare disease. Melbourne: Rare Voices Australia, 2020. http://www.rarevoices.org.au/news/3229/covid-19-pandemic-critical-care-guidelines-for-australians-living-with-a-rare-disease (viewed May 2020). ■