

People at the Centre Update 7

Having a rare condition can place a person at increased risk of contracting COVID-19 and/or at increased risk of mortality from the virus.

The pandemic has left many families isolated and struggling to access support, as well as experiencing problems in accessing ongoing care and treatment for their condition.

Findings from the EURORDIS Rare Barometer COVID-19 experience survey and weekly meetings during April, May and June 2020 show:

- 2/3 of people say that routine rare condition healthcare has been interrupted and has probably or definitely been detrimental to their wellbeing.
- More than half avoiding hospital for fear of contracting the virus
- 1 in 5 people affected by a rare condition have experienced disrupted access to their usual medication.
- The switch to remote consultations has delivered mixed results for people living with rare conditions.
- Support for people living with rare conditions has been reduced or taken away including psychological services, home care, respite care and day care.
- 9% of people affected by a rare condition who thought they should have been tested for COVID-19 actually accessed a test.

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Hospital care is severely affected – 80% of the community receive care in hospitals, however, 40% reported closure of units and for 16% necessary equipment for their hospital care was absent because it was needed for COVID-19 care.

Four recommendations from the survey are:

- A clear and short timetable for the reintroduction of services should be published to give people living with rare conditions clarity as to when they can expect a full service from the NHS.
- People living with a rare condition who have a legitimate reason to ask for a test for COVID-19 (either for diagnosis or in order to assess future risk) should be given priority access.
- When a vaccine or other prophylactic treatment becomes available, patients with rare conditions should be among those with priority access, provided their health condition allows.
- The provision of remote consultations should be continued. Care should be taken to integrate telemedicine into routine care practice with the necessary clinical assurance and data protection safeguards.

[More information on the findings from this survey is available in the report from the Genetic Alliance UK "The rare reality of COVID-19"](#)