

People with rare autoimmune diseases at increased risk of dying during COVID-19 pandemic

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A new study, led by experts from the University of Nottingham, has shown that people with rare autoimmune rheumatic diseases are at a greater risk of dying at a younger age during the COVID-19 pandemic.

The findings of the study, published in the British Society for Rheumatology's journal, *Rheumatology*, was the work of a team of doctors and researchers from RECORDER (Registration of Complex Rare Diseases Exemplars in Rheumatology), which is a joint project between the University of Nottingham and the National Disease Registration Service at Public Health England.

Experts looked at the [electronic health records](#) of 170,000 people in England with rare autoimmune rheumatic diseases. During March and April 202 (the first two months of the COVID-19 [pandemic](#)), the team found that 1,815 (1.1%) of people with these diseases died.

Study co-author, Dr. Fiona Pearce from the School of Medicine at the University of Nottingham, said: "People with rare diseases often have poorer health outcomes generally, so we wanted to find out what impact the COVID-19 pandemic has had. From our study we know that during the early months of the pandemic, people with these diseases were more likely to die than the general population.

"The next steps in our research are to look at death certificate data and

find out why people have died. We'll be examining whether it's due to COVID-19 infection or how much is due to the disruption to healthcare services."

The results also showed that:

- The risk of dying during COVID-19 for people with these conditions increased from age 35
- Women with rare autoimmune rheumatic diseases had a similar risk of death to men during COVID-19—whereas usually their risk of death is lower
- For people of working age with rare autoimmune rheumatic diseases, the risk of dying during COVID-19 was similar to that of someone 20 years older in the [general population](#)

Paul Howard, Chief Executive of Lupus UK, said: "This study is an important step in helping us to understand the impact of the COVID-19 pandemic on people with rare autoimmune rheumatic conditions in the UK. The findings demonstrate that, as a group, people with conditions such as lupus have been disproportionately impacted and therefore the provision of additional support is necessary.

"We hope that the next steps of this research will lead to a clearer understanding about whether COVID-19 or other factors caused the [increased mortality](#), and also whether other health and quality of life measures have been disproportionately affected in these patient groups." Paul Howard, Chief Executive of LUPUS UK."

Dr. Peter Lanyon, Consultant Rheumatologist at Nottingham University Hospitals NHS Trust, said: "Our study illustrates the unique ability of collaboration with the National Disease Registration Service to generate findings that can improve health in [rare diseases](#). Further work to understand them in greater depth and more support for people with rare

autoimmune rheumatic diseases is now needed."

Dr. Sanjeev Patel, President of the British Society for Rheumatology, said: "These results are incredibly important to the rheumatology community. These conditions might be rare, but when we look at them together it's a significant number of people.

"This is a large study which shows for the first time that a subgroup of patients in our care are at an increased risk of dying during the pandemic and at a much younger age. We don't yet know the reasons why, but this study brings into sharp focus the need to be more vigilant with these patients and it should help inform future shielding advice."

More information: Emily Peach et al, Risk of death among people with rare autoimmune diseases compared to the general population in England during the 2020 COVID-19 pandemic, *Rheumatology* (2020). [DOI: 10.1093/rheumatology/keaa855](https://doi.org/10.1093/rheumatology/keaa855)

Provided by University of Nottingham

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