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*Assessing the impact of Coronavirus (COVID-19) on those living with a rare disease*

***Common Variable Immunodeficiency report***

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QUEEN'S UNIVERSITY BELFAST

IMPaCCT study

UNIVERSITY OF ABERDEEN

Investigating the **impact** of COVID-19 on Caregivers and patients.

**Do you have cancer or a pre-cancerous condition?  
Do you have a rare disease?  
Are you a caregiver?**

Tell us how the coronavirus (COVID-19) pandemic is affecting you by clicking on the link below:

<https://www.surveymonkey.co.uk/r/IMPACCTsurvey>

*This data is extracted from a larger project – the IMPaCCT study:*

**The IMPaCCT of the COVID-19 pandemic on people with a rare disease**

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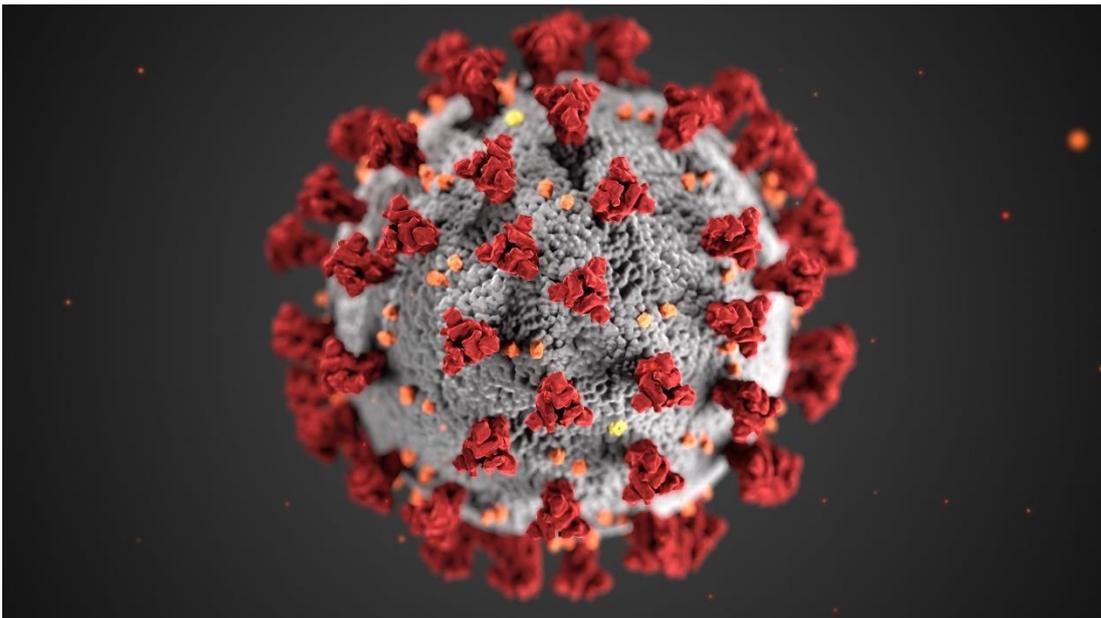
## *Background*

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Coronavirus disease (COVID-19) is an infectious disease caused by a virus which affects the lungs and airways. It first emerged in Wuhan City in China at the end of 2019. From there the virus spread to other countries worldwide with the World Health Organisation declaring it a pandemic on 12<sup>th</sup> March 2020.

The virus placed enormous pressure on health services which were faced with an increasing number of patients requiring respiratory assistance. As a result, normal care pathways were altered. In the UK, and many other countries, routine primary care and hospital appointments were delayed.

Rare diseases are defined by the European Union as those affecting fewer than 1 in 2,000 individuals, cumulatively affecting 1 in every 17 persons at some point in their lives. It is estimated that 350 million people globally have a rare disease. The ongoing COVID-19 global pandemic has disrupted many sources of support and care for those affected by rare diseases, bringing a range of impacts on healthcare, mental and physical health, social life and work life. The pandemic has highlighted the already too prevalent problems faced by our rare disease community.



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## *General Survey*

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An online survey was conducted in Spring 2020 to assess the health, healthcare and psychosocial impact of coronavirus (COVID-19) on patients with rare diseases. The survey queried:

- Experience of isolating/self-isolating;
- Substantial life changes and reasons for such changes;
- How difficult these life changes have been;
- Challenges experienced when speaking to medical professionals;
- Concerns about the impact of COVID-19;
- Further information/services/support that would be useful;
- Improvements required to the support available;

The data was anonymised and analysed Thematically. Specific questions which provided written accounts on the impact of isolation and impact on care due to COVID-19 were selected for analysis. The responses given were searched for similarities and differences as well identifying the meaning of the answers given. Keywords and similar opinions were denoted categorical “codes”. The coded responses were then categorised into overarching Themes that captured all variable “codes” for a given question.

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## *Respondents*

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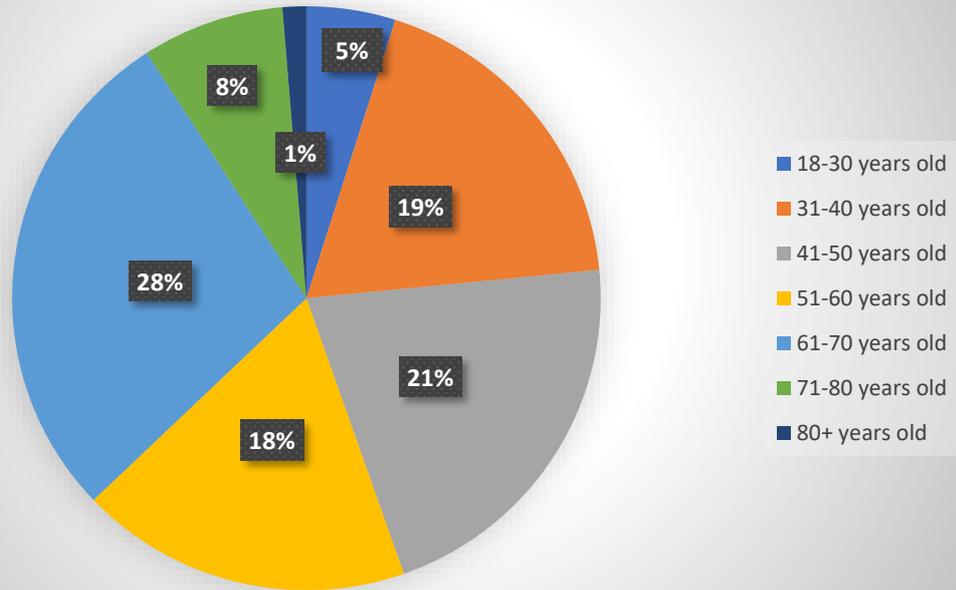
### *Rare disease respondents*

- 424 people with a rare disease (rare disease/rare cancer) responded to the survey.
- The largest number of respondents were 61-70 years old.
- 294 respondents reside in United Kingdom, 57 of those were from Northern Ireland.

### *Caregivers respondents*

- 165 caregivers responded to the survey (8 cancer and rare disease / 157 rare disease)
- The largest number of respondents were 41-50 years old.
- 148 respondents reside in the United Kingdom, 6 of those were from Northern Ireland.
- Carer results were not sub-grouped by disease.

## Age range of rare disease respondents



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### *Common Variable Immunodeficiency*

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Common variable immunodeficiency (CVID) is an immune system disorder that causes low levels of the proteins (immunoglobulins) that help fight infections. The cause of CVID is unknown in the vast majority of cases but in around 10% of people, a genetic mutation has been identified. Researchers believe that the condition is caused by a combination of both environmental and genetic factors.

Someone with CVID, will likely experience repeated infections in their ears, sinuses and respiratory system. In addition, they will have an increased risk of digestive disorders, autoimmune disorders, blood disorders and cancer. CVID can be inherited, or it can develop during your lifetime.

The symptoms of CVID vary between individuals with some appearing in childhood or adolescence, while others don't have any symptoms until adulthood. Because of this the long term outlooks for people with CVID varies greatly.

Treatment for CVID includes immunoglobulins replacement therapy which stops the cycle of infections.

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## *Common Variable Immunodeficiency specific results*

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***Twelve individuals (11 England, 1 Scotland) with Common Variable Immunodeficiency responded to the survey.***

### Social experience

- Respondents reported missing social events such as holidays, theatre trips and dining out. Individuals made the most of garden space.
- Worry expressed about other family members who they can no longer visit.
- Isolation impacted on physical health due to lack of exercise.
- Difficult to stay at home for long periods.
- Individuals reported their desired to spend time with family and friends.
- Many found isolation exhausting.

### Psychological experience

- Some respondents experienced stress as a result of being the house with young children alone for such a long period of time.
- Isolation had a negative impact on mental health and not knowing how long it could last made it more difficult to cope with.
- Anxiety, boredom, frustration and stress were all feelings reported by respondents.

### Impact of COVID-19 on daily lives

- Lack of exercise was reported as impacting on personal fitness.
- Concerns expressed of how others behaviour could impact them, for example the public's inconsistent use of facemasks.
- Financial worries were reported.

### Communication and support

- Relevant information must be made more accessible.
- Disease specific information was requested.

### Access to healthcare and support

- Contact with medical professional via telephone was difficult.
- Individual's expressed concerns about the availability of medication.
- Lack of contact and correspondence from healthcare professionals was disappointing.
- Individual's reported that hospital appointments were delayed or cancelled causing many to worry about the impact this could have on their condition.

## Common Variable Immunodeficiency Summary



- Missing social events.
- Worry about family members.
- Isolation impacted on physical health and was exhausting.
- Difficult to stay at home for long periods.
- Missed time with family and friends.



- Stress as a result of intense childcare.
- Isolation negatively impacted mental health.
- Anxiety, boredom, frustration and stress.



- Lack of exercise impacted fitness.
- Concerns of the impact of others behaviour.
- Financial worries.



- Relevant, accessible information needed.
- Disease specific information requested.



- Telephone consultations difficult.
- Concerns of medication availability.
- Disappointed regarding lack of contact.
- Worry about delayed or cancelled appointments.

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## *Conclusion*

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Those with CVID worried about family members they could no longer see in addition to missing the time spent with family and friends. The stress of being at home for long periods of time was reported, this was often made more difficult due to intense time looking after young children. The lack of exercise was impacting on those with CVID. Similar to other rare conditions, clearer information was requested. Those with CVID found telephone consultations with health professionals difficult and felt disappointed with the lack of contact.

Restrictions and regulations to fight COVID-19 have ultimately exacerbated long-established challenges faced by the rare disease community as well as creating new issues that will have long-lasting effects. There was a wide and varied experience of lockdown reported by those who have rare disease. Both positive and negative responses were included, though there was a predominance of negative and challenging experiences. The diverse range of answers gives an important insight into what these challenges are. The main topics raised through the survey responses were information, long term uncertainty, the lack of practical support, missed social interactions, the changes in healthcare and the impact that is having on wellbeing, and the experience of dealing with healthcare professionals.

Going forward, the mental health aspects of living with a rare disease should be highlighted as equally important to physical aspects, as they often go hand in hand in maintaining patient wellbeing. Mental health services should be treated as a priority and should resume as soon as possible to deal with mental health issues faced by the rare disease community. Also, disease-specific or tailored advice for more vulnerable individuals would also serve to reduce stress and anxiety, and to reassure patients of their safety when attending hospital appointments, returning to work and shopping. These failures to address rare disease issues should be used as a learning curve to ensure problems are met not only in the extreme possibility of a future pandemic but especially under normal circumstances.