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

***Behcet's disease report***

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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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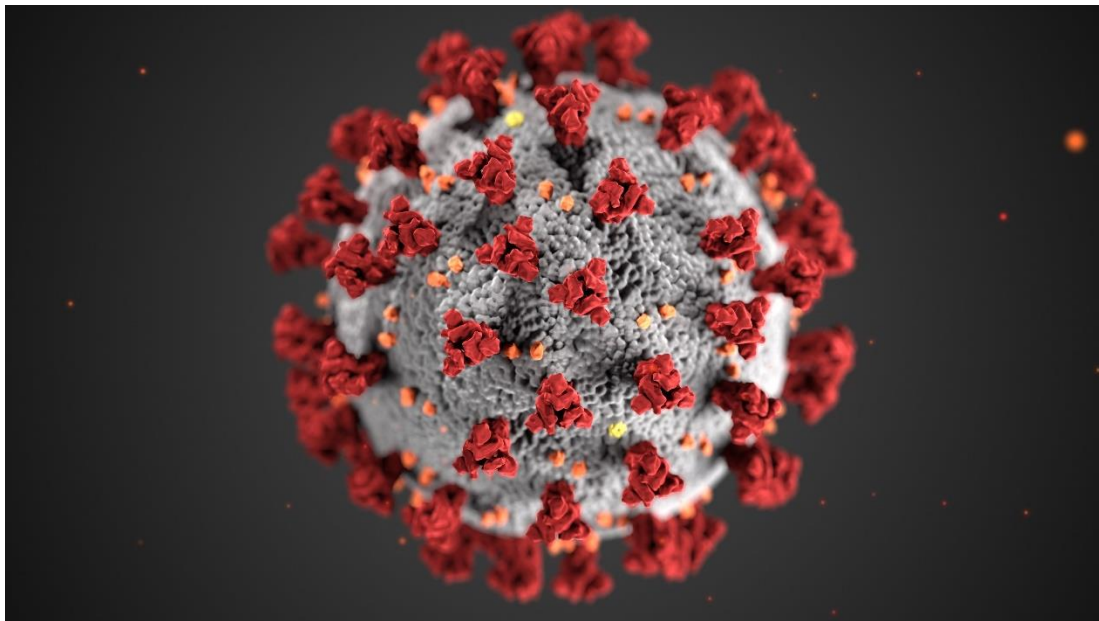
## *Background*

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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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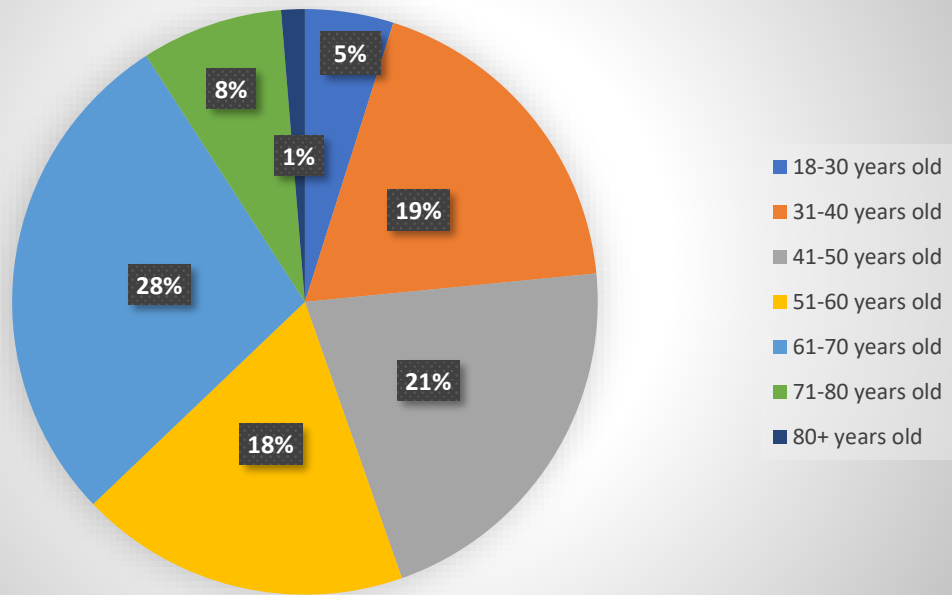
### *Rare disease respondents*

- 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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## *Behcet's disease*

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Behcet's disease is a condition that results in inflammation of the blood vessels and tissues. As many of the symptoms of the disease are similar to other conditions, gaining a diagnosis of Behcet's can be difficult. Most people with the condition experience flare-ups, followed by periods when the symptoms settle down.

The main symptoms are:

- Genital and mouth ulcers
- Red, painful eyes and blurred vision
- Acne-like spots
- Headaches
- Painful, stiff and swollen joints

Permanent vision loss and strokes can occur in more severe cases.

Although the cause of Behcet's disease is unknown, many experts believe it is an autoinflammatory condition where the immune system mistakenly attacks healthy tissue, in this case, the immune system attacks the blood vessels.

Behcet's disease tends to be more common in certain ethnic groups where the genetic variants that contribute to the condition may be more common. Environmental factors are thought to play a role in triggering the condition with lower rates having been detected in people from an at-risk ethnic group who live outside their native country.

Controlling the symptoms of Behcet's is possible with medication that reduces inflammation in the affected parts of the body.

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## *Behcet's disease specific results*

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*Six individuals with Behcet's disease (4 England, 1 Northern Ireland, 1 Channel Islands) responded to the survey.*

### Social experience

- Respondents reported struggles with isolation due to lack of human contact and loss of support network.

### Psychological experience

- Isolation led to many experiencing feelings of depression.
- Increased anxiety and worry were common.
- Respondents would welcome mental health support.
- Lack of physical contact made it difficult to discuss fears properly.

### Impact of COVID-19 on daily lives

- Individuals required improved access to grocery slots.

### Communication and support

- Disease specific communication is needed.
- Confusion over who should be shielding – clearer guidance needed.

### Access to healthcare and support

- Concerns of how COVID-19 has impacted their care.
- Frequent cancellations and delays impacting appointments.
- Scared to go to GP due to risk of contracting COVID-19.
- Concerns were expressed over future appointments.

## Behcet's disease Summary



- Respondents reported struggles with isolation.



- Isolation caused feelings of depression.
- Increased anxiety and worry were common.
- Mental health support would be welcomed.
- Lack of physical contact made it difficult to discuss fears properly.



- Individuals required improved access to grocery slots.



- Disease specific communication requested.
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- Concerns of how COVID-19 has impacted their care.
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## *Conclusion*

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As with many other rare diseases those living with Behcet's struggled with the lack of contact from others and the reduction in support. Feelings of depression and worry were common with suggestions made for increased mental health support. Confusion around the issue of shielding was mentioned by those with Behcet's, a request of clearer guidance was made. Similar to other conditions those with Behcet's had experienced disruption to their healthcare and were worried about what this would mean for the future of their care.

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.