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

Vasculitis report

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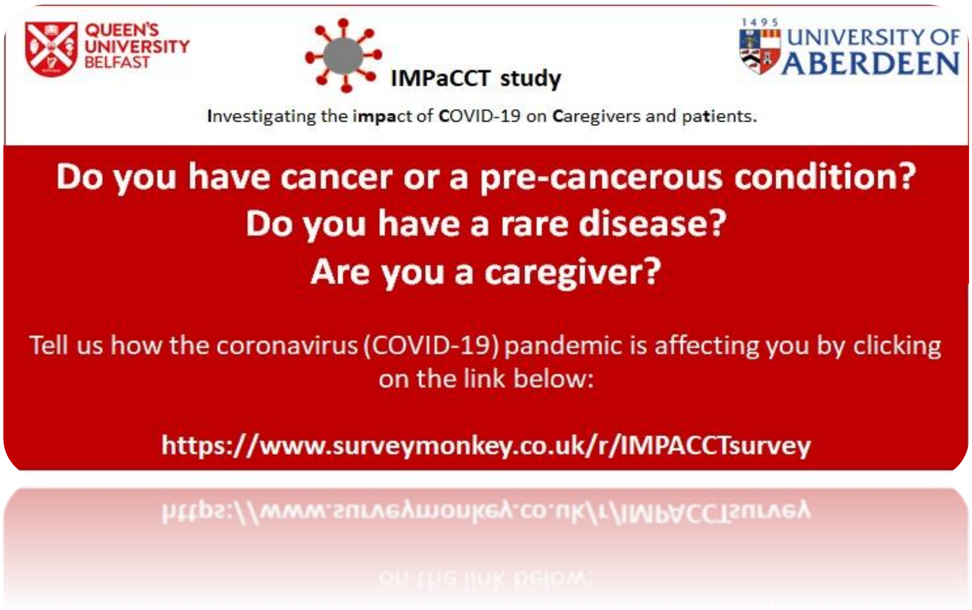

Investigating the impact of COVID-19 on Caregivers and patients.

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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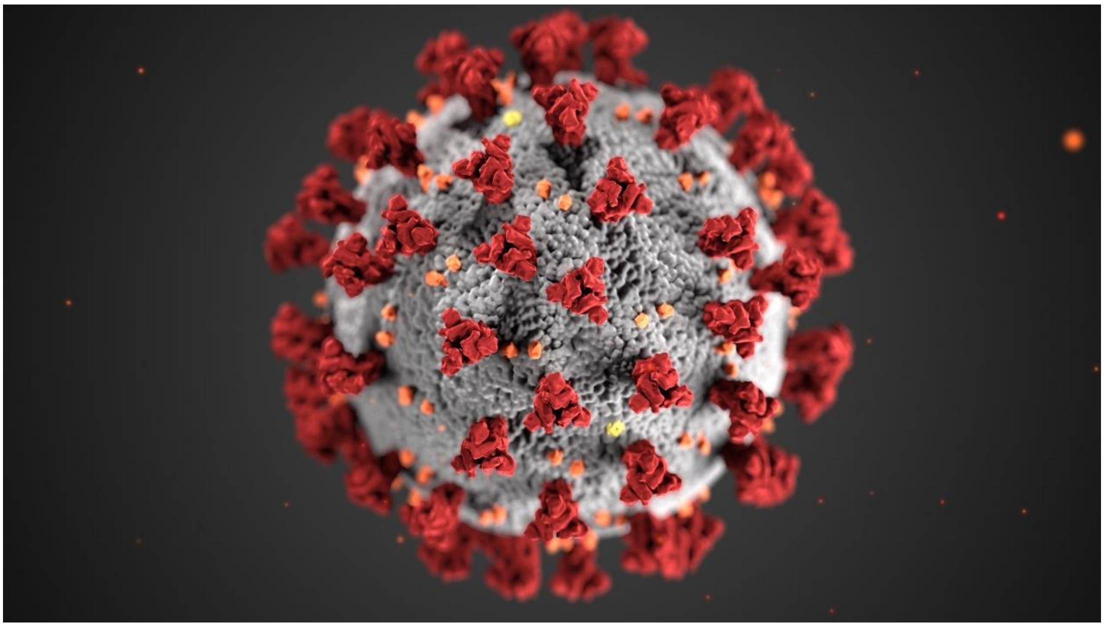
Background

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 12th 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.



General Survey

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.

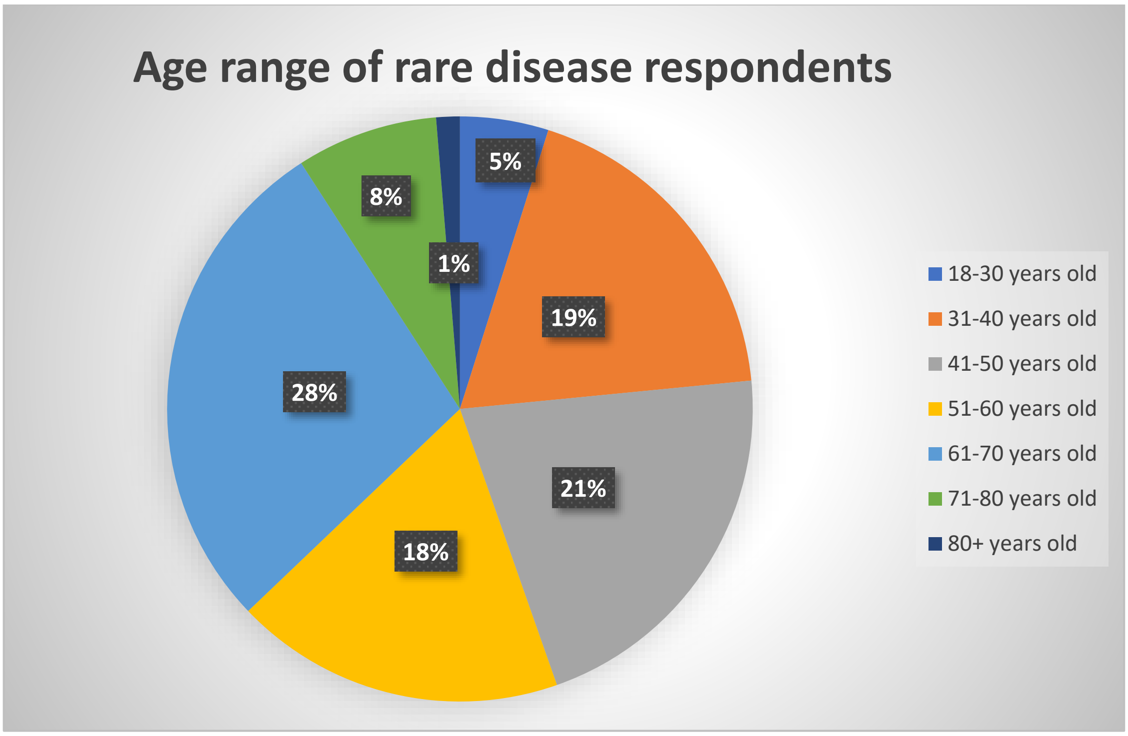
Respondents

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
5%
8%
1%
19%
28%
21%
18%
18-30 years old
31-40 years old
41-50 years old
51-60 years old
61-70 years old
71-80 years old
80+ years old

Vasculitis

Vasculitis involves inflammation of the blood vessels; the immune system attacks healthy blood vessels, causing them to become swollen and narrow. The cause of vasculitis is often unknown but it can be triggered by an infection or a medicine.

The symptoms of vasculitis depend on which organs are affected and diagnosing the condition can be difficult. The condition can range from a minor problem affecting the skin, to a more serious illness that causes problems with organs like the heart or kidneys. There are many types of vasculitis and most of them are rare. The condition can be short term or long lasting and can affect anyone. However, some types are more common among certain age groups.

Some types of vasculitis can improve without treatment, however most types require medications to control the inflammation and prevent flare-ups. People living with vasculitis often attend multiple hospital consultants to manage complications with different organ systems.

Vasculitis specific results

Thirteen individuals (6 Northern Ireland, 5 England, 2 Channel Islands) with Vasculitis responded to the survey.

Social experience

- Isolation felt worse due to not seeing friends and family.
- Respondents reported struggles with isolation due to lack of human contact and loss of support network.

Impact of COVID-19 on daily lives

- Fear over returning to work and being near to other people.
- Balancing family and work life was difficult as many working from home and schools closed for long periods.
- Financial concerns - support requested.
- Individuals required improved access to grocery slots.

Psychological experience

- Stress levels raised.
- Feel frightened.
- 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.

Communication and support

- Conflicting information relating to shielding.
- Lack of disease-specific information.
- Expressed the need for consistent information and guidance.
- Clear guidance needed.
- Usual support withdrawn.
- Advice on how best to keep safe was requested.

Access to healthcare and support

- Unclear of when to seek medical help.
- No contact from healthcare professionals.
- No one knows when ‘normal care’ will resume.
- Advice on what PPE to use would be welcomed.
- 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.

Vasculitis Summary

- Not seeing family and friends made isolation more difficult.
- Respondents reported struggles with isolation.

- Stress levels raised.
- Feel frightened.
- Isolation caused depression.
- Increased anxiety and worry.
- Mental health support needed.
- Lack of physical contact made it difficult to discuss fears properly.

- Fear over returning to work.
- Balancing family and work life was difficult.
- Financial concerns.

- Conflicting information relating to shielding.
- Lack of disease-specific information.
- Consistent information and guidance needed.
- Usual support withdrawn.

- No contact from healthcare professionals.
- Advice on PPE needed.
- Concerns of how COVID-19 has impacted their care.
- Frequent cancellations and delays to appointments.
- Scared to go to GP.
- Concerns were expressed over future appointments.

Conclusion

As with most individuals living with a rare disease, the lack of contact with family and friends was difficult for those with vasculitis. Fears around returning to work and being close to others again was reported. The balance of work and family life was difficult for many. Feelings of depression and worry were common with suggestions made for increased mental health support. Support was requested to help with financial worries. Those with vasculitis would welcome disease specific information as confusion around conflicting advice was common. Lack of contact from healthcare professionals was all too common and those with vasculitis said they would welcome advice around PPE. Similar to other conditions those with Vasculitis 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.