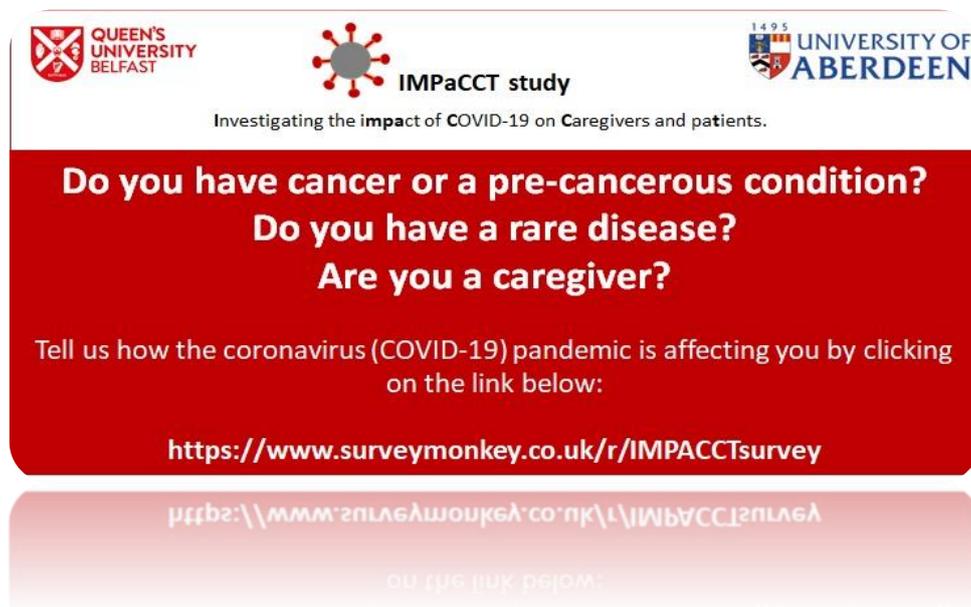

Assessing the impact of Coronavirus (COVID-19) on those living with a rare disease

Addison's disease report

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The banner features logos for Queen's University Belfast, IMPaCCT study, and the University of Aberdeen. The text asks: 'Do you have cancer or a pre-cancerous condition? Do you have a rare disease? Are you a caregiver?' and provides a survey link: 'https://www.surveymonkey.co.uk/r/IMPACTsurvey'. A faint, mirrored version of the banner is visible below it.

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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Centre for Public Health, School of Medicine Dentistry and Biomedical Sciences, Institute of Clinical Science Block A, Grosvenor Road, Belfast, BT12 6BA. <https://www.qub.ac.uk/sites/RareDisease/>

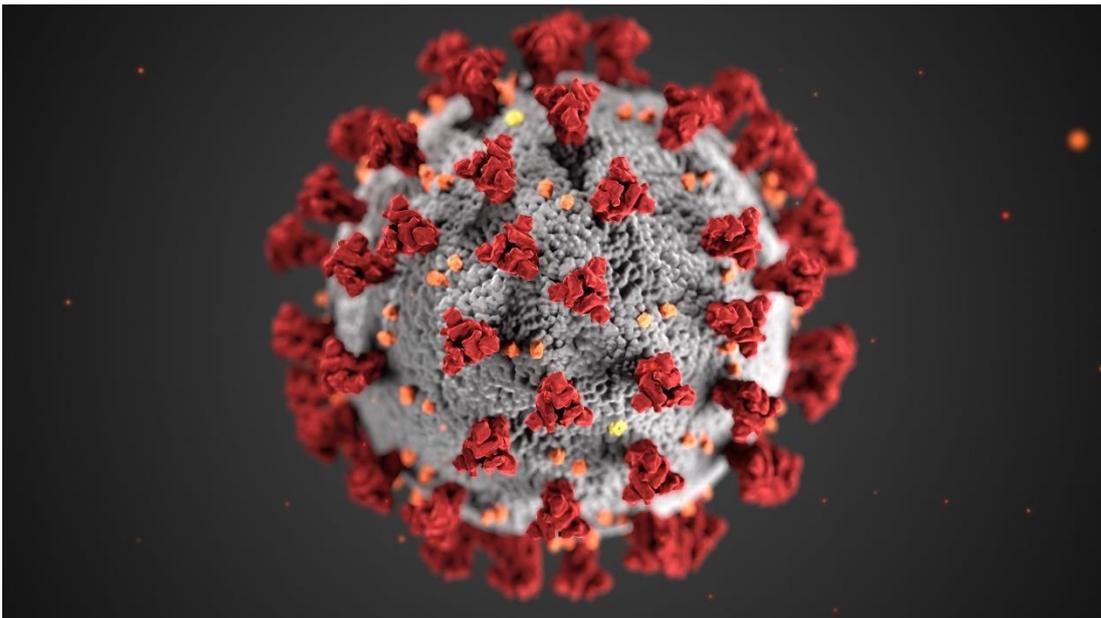
Email contact: raredisease@qub.ac.uk

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

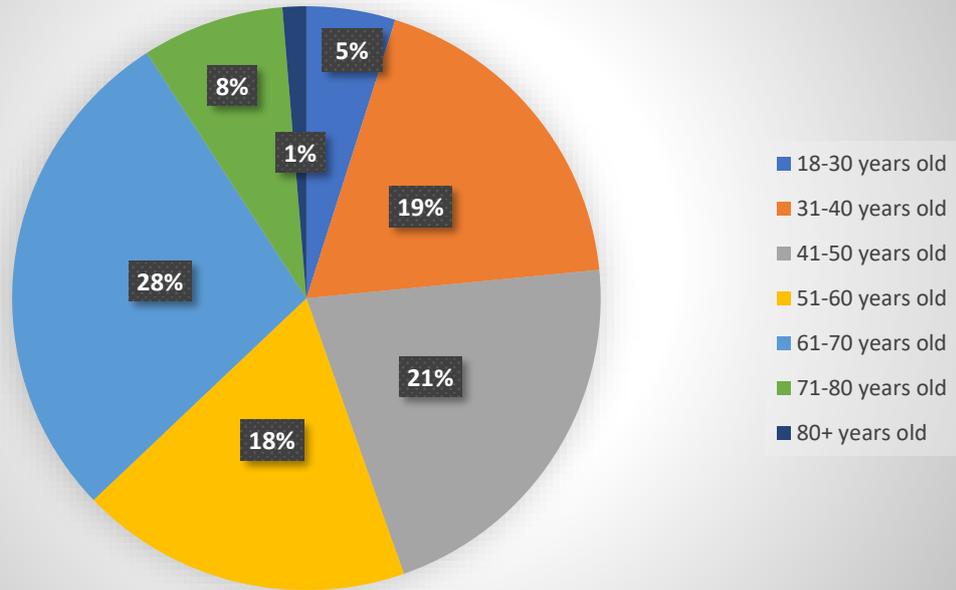
Rare disease respondents

- 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



Addison's Disease

Addison's disease is a rare disorder of the adrenal glands, affecting about 8,400 people in the UK. It is most common between the ages of 30 and 50 and women tend to be affected more than men. The adrenal glands are two small glands that sit on top of the kidneys that produce two essential hormones: cortisol and aldosterone. The condition is usually the result of a problem with the immune system in which the adrenal gland becomes damaged, disrupting the production of cortisol or aldosterone.

Early-stage symptoms of Addison's disease include:

- Lack of energy or motivation (fatigue)
- Muscle weakness
- Low mood
- Loss of appetite and unintentional weight loss
- Increased thirst

These problems will increase in severity over time and further symptoms such as dizziness, fainting, cramps and exhaustion may develop. Small areas of darkened skin, or darkened lips or gums may also develop.

Addison's disease can be treated using medication to replace the missing hormones. Taking medication throughout the lifespan enables Addison's disease to be controlled and an active life to be lead with few limitations.

Addison's Disease specific results

23 individuals (16 England, 2 Scotland, 1 Northern Ireland, 1 Wales, 1 USA, 1 Canada, 1 Channel Islands) with Addison's Disease responded to the survey.

Social experience

- Physical contact with friends and family was missed greatly.
- Those who found isolation particularly difficult to manage reported social disruption as the cause and also said they desperately missed and worried about their children.
- Feelings of boredom were common during periods of isolation.
- Reports of feeling safer when isolating.
- Individuals tried to make the most of isolation by appreciating the simple things such as going for walks, enjoying local wildlife and making Zoom calls to family.

Psychological experience

- Fear of going out and states of constant worry were reported.
- Individual's felt 'down' from time to time.

Impact of COVID-19 on daily lives

- Feelings of guilt about not being able to work were common.
- Balancing childcare and work life was a continual struggle.
- Individuals missed getting out for exercise and leisure.
- Difficulties were experienced when accessing grocery supplies.
- Stress experienced because of individuals gaining weight.
- Working from home was difficult.

Communication and support

- Feels relentless and drained due to lack of support were common.
- Worry about consequences if they were to contract COVID due to their health condition.
- Feel Addison's disease should be on the shielding list.
- Conflicting information caused much frustration.
- Lack of information about shielding and lack of Addison's Disease specific information.
- No one seemed to know what to do which resulted in confusion.
- Consistent information would be welcomed.
- Individuals would value the opportunity to speak to others with same condition / or an Addison's disease specialist.

Access to healthcare and support

- No contact from healthcare professionals lead to individuals feeling ignored.
- Feelings of disappointment in the healthcare system were common.
- Individuals were scared that health issues could be missed or overlooked.
- There was worry that hospital staff would not know how to treat them due to their condition.
- Concerns about how COVID-19 has affected their healthcare, particularly cancellations, delays and lack of in-person appointments.
- Fear of contracting COVID-19 at healthcare appointments was reported.

Addison's Disease Summary



- Contact with friends and family greatly missed.
- Feelings of boredom were common.
- Some felt safer when isolating.



- Fear of going out and constant worry were reported.
- Individuals felt 'down' from time to time.



- Guilt about not being able to work.
- Delicate balance between childcare and work life.
- Missed exercise and leisure.
- Access to groceries.
- Weight gain.



- Relentless and drained due to lack of support.
- Worry regarding the impact of COVID due to their health condition.
- Felt they should be on shielding list.
- Conflicting information.
- Disease specific information needed.



- Feel ignored by healthcare professionals.
- Worry that hospital staff would not know how to treat them.
- Cancellations and delays to appointments.
- Worry of contracting COVID at appointments.

Conclusion

Fear and worry appear to be more prevalent in those with Addison's disease than other rare diseases. Individuals with this condition also appeared to be struggling more with practical day to day activities such as working, lack of exercise and access to groceries. Communication issues were evident across all rare diseases however those with Addison's disease particularly highlighted the challenges with a lack of disease specific advice and suggested that speaking to others with their condition would be beneficial. The effect on healthcare was experienced by many and those with Addison's disease felt they have been 'let down' by such services.

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.