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

Ataxia report

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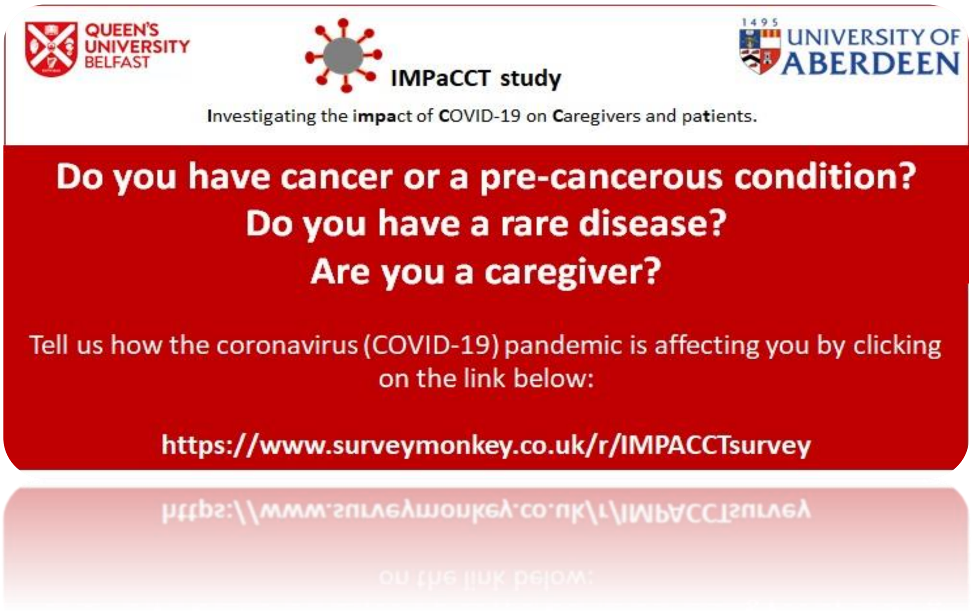

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IMPaCCT study

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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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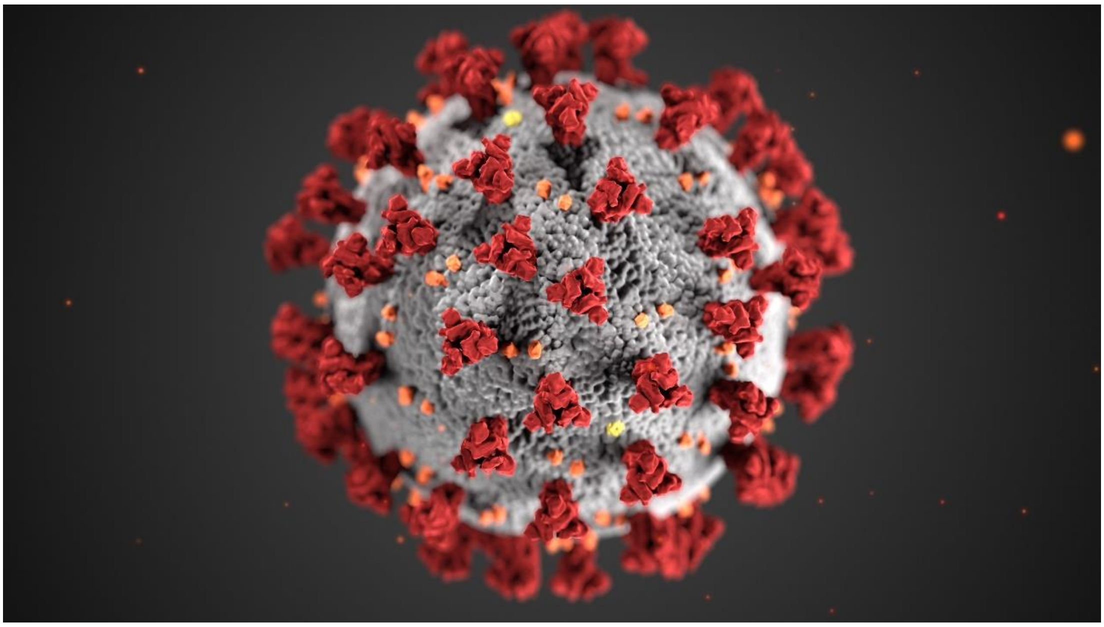
Background

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.

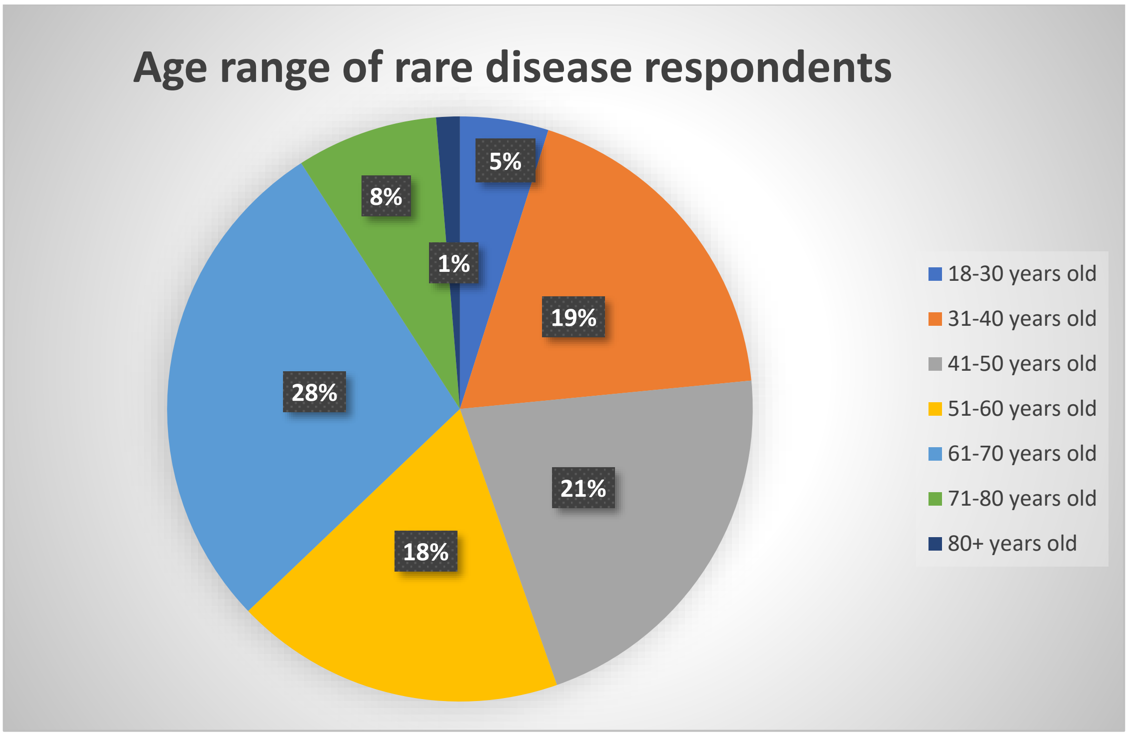
Respondents

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

Ataxia

Ataxia is a lack of muscle coordination that may affect a person's speech, eye movements, and ability to swallow, walk and pick up objects, along with other voluntary movements. There are many different types of ataxia that affect people in different ways. There are at least 10,000 adults and around 500 children in the UK with progressive ataxia.

Any part of the body can be affected by ataxia, but people with ataxia often have difficulties with:

- Balance and walking
- Speaking
- Swallowing
- Tasks that require a high degree of control, such as writing and eating
- Vision

The exact symptoms and their severity vary depending on the type of ataxia a person has.

There are many different types of ataxia, which can be divided into three broad categories:

- acquired ataxia – where symptoms develop as the result of trauma, a stroke, multiple sclerosis (MS), a brain tumour, nutritional deficiencies, or other problems that damage the brain or nervous system
- hereditary ataxia – where symptoms develop slowly over many years and are caused by faulty genes that a person inherits from their parents; the most common type is Friedreich's ataxia
- idiopathic late-onset cerebellar ataxia (ILOCA) – where the brain is progressively damaged over time for reasons that are unclear

In most cases, there is no cure for ataxia and supportive treatment to control the symptoms is necessary. The outlook for ataxia can vary considerably. It largely depends on the type of ataxia you have. Some types may remain relatively stable or even improve with time. But most will get progressively worse over many years.

Ataxia specific results

Thirteen individuals (11 England, 2 Scotland) with Ataxia responded to the survey.

Social experience

- Physical contact with friends and family was greatly missed.
- Isolation was difficult to manage.

Psychological experience

- Feelings of depression were common due to no contact with family or friends.
- Isolation difficult to cope with mentally.

Impact of COVID-19 on daily lives

- Financial concerns were prominent with individuals being furloughed.
- Lack of exercise caused a deterioration of mobility.

Communication and information

- Not enough is known about Ataxia, more knowledge and awareness is required.
- Concise Government advice would be welcomed.
- Difficult to make informed decisions without sufficient information.

Access to healthcare and support

- Respondents requested improved healthcare contact.
- Individuals have many unanswered questions regarding COVID-19.
- Medical appointments were difficult to schedule.
- COVID-19 affected the care received by those with a rare disease with little medical contact and delayed appointments being common.
- Conflicted feelings reported about attending hospital and the risk this poses on them due to low immunity.

Ataxia Summary

- Missing contact with friends and family.
- Isolation was difficult.

- Feelings of depression were reported.
- Isolation impacted mental health.

- Financial concerns due to furlough.
- Lack of exercise was negatively affecting mobility.

- More knowledge and awareness of Ataxia is needed.
- Concise Government advice would be helpful.
- Difficult to make decisions without access to information.

- Improved healthcare contact.
- Unanswered questions.
- Medical appointments are difficult to schedule.
- Care affected.
- Risk of attending hospital is a difficult balance.

Conclusion

As with other rare conditions, persons with Ataxia missed contact with friends and family. The mental impact of obvious in those with Ataxia with reports of depression and the difficulties associated with isolation. People living with Ataxia highlighted the lack of knowledge of their condition and the impact this had on the support and information available. Those living with Ataxia had many questions relating to their healthcare and felt conflicted about the risk attending hospital poses on them.

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.