



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

## Do you have a rare disease?

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

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

A rare disease is defined as a disorder that affects less than 1 in 2,000 people.

Respondent selected 'rare disease' response  
*(includes cancers, but not all rare cancers)*

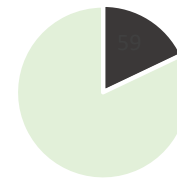
## Preliminary research report

Terms of use: These represent the preliminary findings of the IMPaCCT study. They are to be used solely for background information purposes for the Northern Ireland Rare Disease Partnership. The full report with a larger dataset will be available in June 2020.

# Demographics

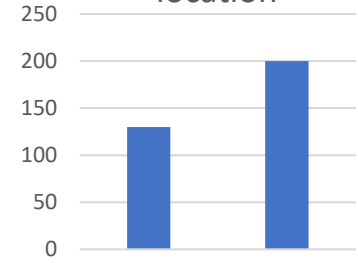
- 82% female
- 77% aged 30-70 years old
- 84% further or higher education
- 65% are married
- 28% have children
- 61% live in urban area
- 57% have 1-2 people at home

Gender



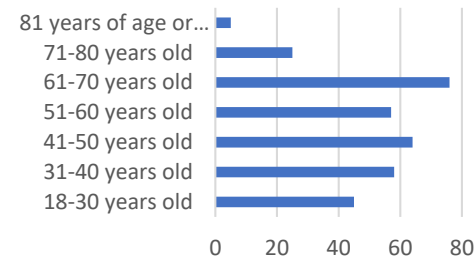
■ male ■ female

location

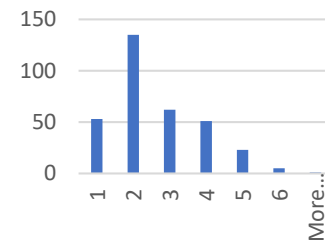


Rural area Urban area

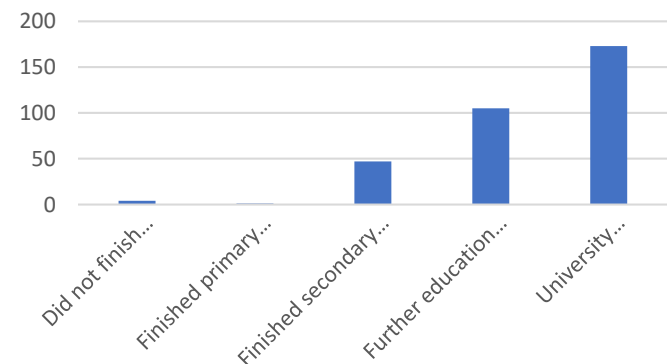
Age of respondents



People in household

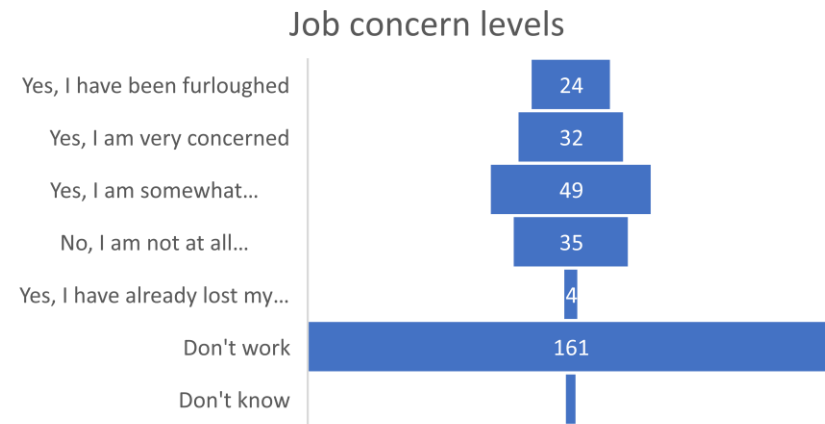


Education



# Impact on work

- 52% don't work
- Of those working,
- 55% are concerned
  - 19% lost job or furloughed
  - 80 are working remotely
  - 83 'essential job'
- 
- 65% have no carer role
    - Of the 35% also caring, 60% provide care for people they live with



12% suspect COVID-19

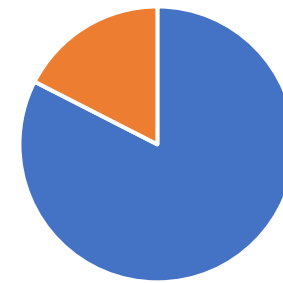
# Isolating...

- 68% are isolating
  - 87 > 1 month
  - 15 > 2 months
- 83% of people's lives changed

# Guidelines...

- 52% confident understanding
- 32% think they understand
- (lower than cancer and general public respondents)

Life changed from COVID-19?



■ Yes ■ No

# Self isolating experiences...

- **Positive:**
  - Calming.
  - Time to try new hobbies/get jobs done.
  - No difference to normal routine.
- **Negative:**
  - Miss social interaction.
  - Miss family and friends.
  - Stressful.
  - Tough, difficult.
  - Boring.
  - Frustrating.

*"Challenging! Aside from the lack of face to face human contact (which is almost zero), just practical things that need the help of another person around the home are starting to get really frustrating, and risky".*

*"Boring, lack of space to exercise, missing family"*

*"I quite like it. Feeling safe. Was able to do some work from home and felt of value. Have not been bored at all and have not done much of the long 'to-do' list. Was probably pretty tired going into isolation so maybe needed this".*

# Has your life changed substantially since start of COVID-19?

- Can not see family / friends.
- Financial worries.
- Hospital appointments rearranged.
- Stress, worry, anxiety.
- Intense caring responsibilities.
- No support available.

*"Although I have a rare disease, I'm very independent. As much as I've had family and friends help me out, I miss my independence".*

*"I can no longer physically go to work I have to do it from home which means my motivation for work has gone down significantly".*

*"Going from 4 wages to 1 , plus finding it hard to see the doctors re my condition, not reviving my medication, and my condition flaring up".*

# Found the changes difficult...

- Unsure of how to deal with the changes.
- Feeling constant worry.
- Struggle with missing family/friends.
- Miss independence.
- Negatively impacting physical and mental health.

*"My whole world has been completely changed nothing is normal. And as I'm recommended to shield the change in guidelines cannot even make a positive impact on my life".*

*"I do not take easily to being kept indoors for days/weeks. I want my life back".*

*"It's worsened my health physically and mentally. Struggling to deal and cope with everything. It's hard to manage when you lose all you are dependent on".*

# Challenges when speaking to medical professionals...

- Poor communication/difficult to make contact.
- Difficult to get an appointment with GP.
- Advice tends to be general, no specific guidance.
- Difficulties accessing medicines.
- Unclear/conflicting advice.
- Remote appointments.
- Lack of knowledge.
- Difficult to make contact.

*"No clear advice given".*

*"Access is very difficult".*

*"No one responded to my emails for 5 weeks when i was looking for advice re self isolating or shielding".*

*"All feels very general and not specific".*

*"Inconsistency whether my condition is classed as high risk".*



# Impact COVID-19 has had on your health during this past month...

- Positive impact (n=15).
- Slight negative impact (n=134).
- Severe negative impact (n= 46).
- No change (n=79).

*"Physically despite my efforts I have not been able to exercise as I would normally".*

*"I can't leave the house so impacts mental health. Physically I'm doing less and less, which is bad for my primary rare disease".*

*"Mental health in a bad way. ...No proper food for my health...Just eating what we have prices have jumped all over and distance is a problem".*

# Concerns about the impact COVID-19 will have on the care received as a rare disease patient ...

- Missing appointments / disruption to treatment.
- Infection.
- Risks of entering hospitals / GP surgeries.
- Access to medicines.
- Lack of respite / care support

*"I am not receiving any care. I am concerned if I get the virus that hospital staff will not know how to treat me properly. They do not know how to treat me when I go to the hospital anyway without adding another complicating factor".*

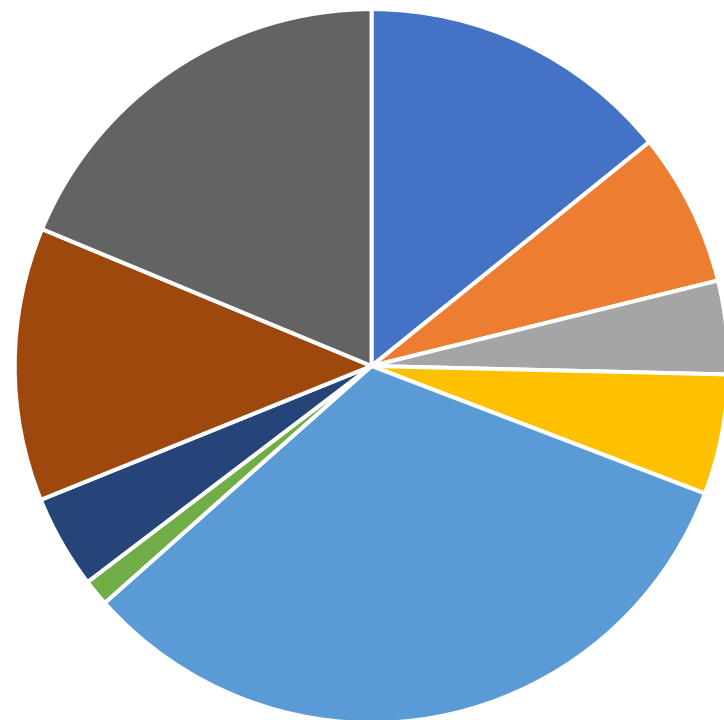
*"I worry that I cannot see people face to face and cannot have the appropriate appointments with my consultant".*

*"I dread having to go into my doctor's appointments with the pandemic still going on".*

*"I'm afraid that eventually I won't have access to my medication and medical appointments".*

# Where has useful information been found regarding rare disease and coronavirus (COVID-19)?

NHS website / Healthcare system website	14.2%
Online forums	6.9%
Healthcare workers	4.2%
Television	5.4%
Rare Disease charity specific websites	32.6%
Newspapers	1.2%
Social media platforms	4.2%
Other (please specify)	12.4%
Did not answer	18.7%



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# Further information/ services/support which would be useful for you at this time:

- Telephone call from doctor/GP for support
- Mental Health Support
- Access to research/journals
- Practical information about appointments and healthcare systems. Travelling for treatment?
- Personally tailored information from consultants/specific to your rare disease
- COVID action plan, guidelines, rationale
- Better government communication, true facts
- Awareness of challenges for those with rare disease amidst COVID19
- Access to home delivery slots and affordable food
- Access to back-up care and respite / school services
- Availability of necessary resources/equipment
- Financial support when medically isolating
- Letter/Advice on Shielding/isolation/working, confirming advice to do with rare disease

*“Excellent scientific reporting . Access to scientific papers and journals.”*

*“Access to grocery deliveries. I have been told that I have been identified as high priority but can never access it.”*

*“Mental health support via health professionals, helplines and online advice is not appropriate for everyone, particularly when the relationship between physical health diagnosis and poor mental health is already established and not just a reaction to the pandemic.”*

*“It would be nice to have a 'check in' from specialist teams and be given the chance to ask questions about risk or mention any troubling symptoms, new or otherwise.”*

*“More information on social distancing for my specific condition and meds. One consultant says one thing and the other says another. Tad confusing.”*

*“Information on what high risk patients are able to do after isolating/shielding for 12 weeks. Will there be further isolation period to follow?”*

# Some rare disease carer concerns:

- Many carers are working much longer hours due to staff shortages. Funding for carers?
- Lack of carer support – no readily available carer ‘backup’ staff, no schools or respite facilities.
- Rare disease patients may have complex care needs that are optimally managed by their primary carers. Can that essential care still be provided in hospital during this pandemic?
- Challenges sourcing relevant PPE
- Lack of delivery slots for grocery / pharmacy / general goods.
- Lack of understanding of the guidelines – different information perceived from health and social care, support groups, and the government
- Worry about where to stay if travelling for medical care – this is not an exemption for hotel stays while accommodations are ‘closed’
- Worry about restrictions lifting...

*“There is no backup and no support”*

*“We have direct payments and usually source our own PPE, but suppliers are focused on NHS provision only”*

*“How do I get essential items?  
I daren’t take my son out.”*

*“I love my child, but there is no break – 24/7 with schools and respite facilities closed”*

*“Can family members be paid from Direct Payments as we can’t take the risk finding / hiring new people during this pandemic?”*

*“If the person I care for gets ill we usually stay in hospital to look after their 24/7 care needs – what happens now? Hospital staff usually don’t understand about ... rare disease needs”*

*“More information on social distancing for us – the advice is contradictory”*

*“What about exiting lockdown? The public needs more education on social distancing to help very high risk people”*

Those in Northern Ireland who did not feel sufficient support has been given to those with a rare disease since the coronavirus (COVID-19) pandemic began when asked “what more do you feel could be done to improve the support available?” answered:

*“Not everyone understands that although we don't have shielding letters, why it is crucial we cant catch something like this”*

*“Clear outline of what measures are put in place for my care to continue, everything has just stopped. No letter to outline alternatives “*

*“lots! less contradictions in advice. better planning. more financial support for vulnerable people / those with shielding family members in same household. “*

*“including rare disease patients in the "at risk" category”*

*“Local online meetings to discuss our concerns”*

*“Contact direct from clinical team”*

*“Activities could be set up online to help people live with a rare disease look after their mental health and physical health etc.”*

*“More information about supporting rare disease patients and their carers. More 'policing' of social distancing in shops e.g. if carer is reaching up for a loaf of bread, a stranger's head should not appear under their arm! More public education about the importance of social distancing for vulnerable groups. maybe a 'please give me space' tag/banner I could use when lockdown is relaxed...”*