



CHRONIC ILLNESS AND COVID-19

INTERIM REPORT

ABOUT RAiISE

RAiISE is an organisation inspired by the negative experiences that young people face while studying and living with chronic, often invisible illnesses. Many young people who live with invisible illnesses look no different to their healthy peers – yet face a significant amount of difficulties as a result of their health conditions. RAiISE aims is to improve the support provided to young people with invisible illnesses in school, college and university, through delivering resources to education professionals. RAiISE also advocates for young people with chronic illnesses, helping to empower young people to take control.

ABOUT THE REPORT

COVID-19 was declared a global pandemic by the World Health Organisation on 11 March 2020. RAiISE launched an online survey on 01 June 2020 as the United Kingdom began to relax some of the imposed restrictions during the pandemic. Our goal for the survey was to understand people's experiences of living with chronic illnesses during the COVID-19 pandemic, including how the pandemic has impacted people's health, wellbeing and care. We also wanted to identify people's priorities for the weeks and months ahead, so that we could help to inform the wider community of what matters to those still living with chronic illnesses.

If you have any questions, thoughts or ideas, please get in touch.

Sophie
Sophie Ainsworth
Founder and CEO



CHRONIC ILLNESS AND COVID-19

COVID-19 HAS INDIRECTLY WORSENERD HEALTH



8 OUT OF 10*

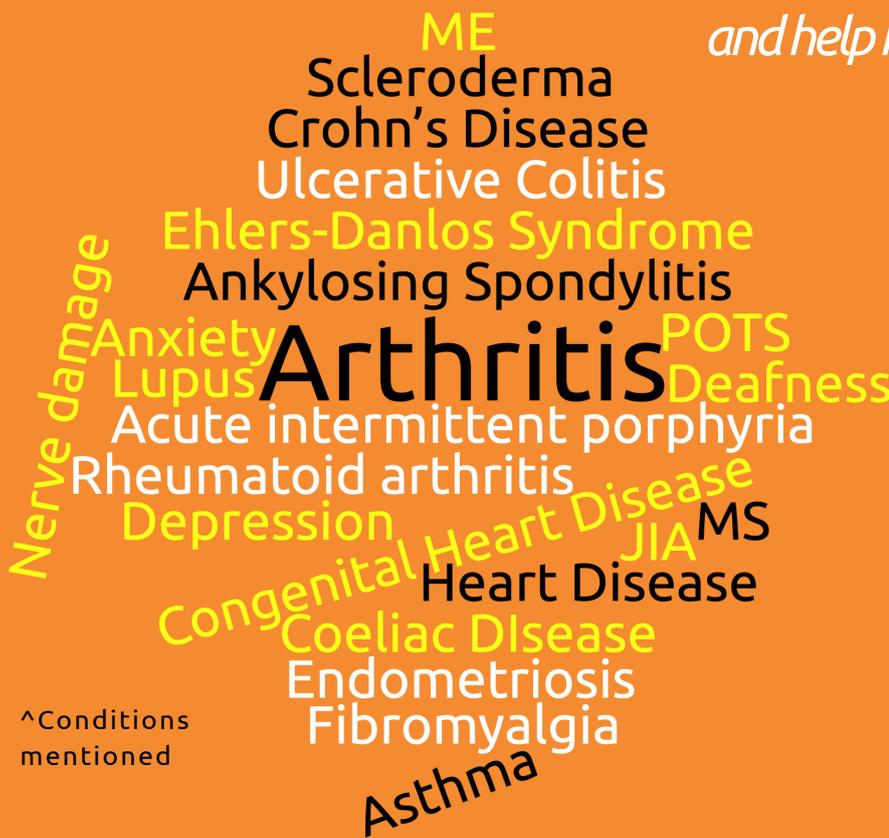
people said that their health has been negatively impacted during the COVID-19 pandemic (indirectly, excluding contracting coronavirus).

**Based on a total of 131 responses in a survey asking how COVID-19 had impacted the lives of young people living with chronic illnesses.*



percent of people are continuing to shield, despite relaxing of government guidance.

"Access to health care professionals and help has been non-existent."



^Conditions mentioned



"Being unable to access the medical treatment I need and previously received on a regular basis that kept my health somewhat stable, my health has rapidly declined. I've been at a point where I know I need to go to hospital but don't because I'm too scared of contracting the virus."

THE FIVE MAJOR CHALLENGES

Identified within the survey and summarised into key themes...

To shield or not to shield?

Shielding guidance has been confusing and poorly communicated, resulting in a lack of trust between people, healthcare professionals and the Government.

"My health has gone downhill rapidly, I am experiencing more pain, more irreversible damage. More flare ups. With little or no access to treatment, medication and carers."

Money doesn't grow on trees

Less income and more expenditure is adding to people's worries at an already challenging time.

"My urgent cardiology referral will be another 6-12 month wait. This is devastating and means we are now having to save for private care."

Usual care has disappeared

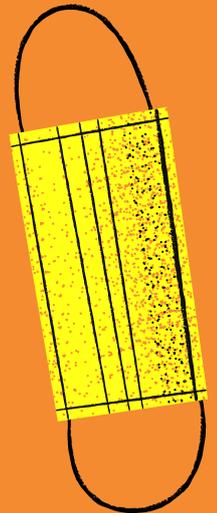
Although the NHS has remained 'open', some people have been refused access to care. Others have been unable to access medicines used to treat their conditions (e.g. hydroxychloroquine for lupus), physiotherapy and other appointments, which has resulted in a deterioration in people's health.

This all feels too much

Stress, loneliness and the gravity of the pandemic has weighed heavy on people's mental health.

Illnesses have flared up

Stress, lifestyle changes, treatment changes and additional responsibilities have caused people's illnesses to flare up, resulting in increased disease activity, pain and fatigue, among many other symptoms.



PEOPLE'S EXPERIENCES

"It has caused an increased level of anxiety... I had spent the 18 months prior to the lockdown working on using public transport again and the lockdown has interrupted this. I have also seen a physical deterioration especially with my ability to concentrate on a specific task due to the cancellation of A Level exams."

"Been actively suicidal on multiple occasions, eating disorder relapse, OCD compulsions increased, issues remembering to take thyroid medication or issues being able to leave the house to get it due to panic attacks, leading to extreme fatigue. Improper nutrition which over time could lead to further thyroid impairment of function."

"Been waiting 4 months for an urgent referral and left without treatment or assistance. I've just been told it will be another 6-12 months... Most of my appointments and tests have been cancelled, so I have been left on higher doses when originally they should have been lowered by now."

"I have had a flare up during COVID-19 and I cannot access my healthcare team at the hospital. The pain has been unbearable and has made me feel so low, as a result I have been given antidepressants. My mental and physical health has impacted my ability to complete my university assignments."

"The world of lockdown has made society so much more accessible and I really hope that this continues when a new "normal" is established. For a lot of us with chronic illness the lifting of lockdown will make no difference to the isolation we face."

"It's really hard to not have the usual access e.g. to physios and rheumatologists when needed. Knowing that you're in pain and cannot get help is the worst. Also, it's difficult not to be able to see friends to help you when you're flaring or to take your mind off things. Because I'm now working from home, I'm not moving around as much which isn't good for me, and my house has poor heating which doesn't help either."

WHAT WOULD HELP?



ACCESS

Access to usual treatment, appointments and carers - chronic illness does not disappear during a pandemic.



SUPPORT

Support people's mental health so that they know they're not alone, while also providing help with finances and workplace rights.



GUIDANCE

Clear, consistent and regular guidance for people who are shielding, with accurate assessments of risk for every individual.



www.raiiise.co.uk