

“I feel forgotten.”

A submission by the Chronic Illness Inclusion Project to the Women and Equalities Committee inquiry into the impact of coronavirus (covid-19) on people with protected characteristics

Introduction

The Chronic Illness Inclusion Project (CIIP) was a social action research project led by disabled people that ran from April 2017 to December 2019. It was part of the [DRILL programme](#) of disability research and hosted by The Centre for Welfare Reform. The CIIP investigated the lived experience of people with chronic illness in the UK. The majority of our research participants live with “stamina, breathing and fatigue” impairments, which constitute the second largest impairment group in the UK (2017 Family Resources Survey). Our research is the only one of its kind to represent this important sub-group of disabled people within the UK population. Our research findings and associated policy recommendations are contained in a report: [*Energy impairment and disability inclusion: towards an advocacy movement for energy limiting chronic illness.*](#)

The CIIP is now in the process of becoming a user-led advocacy organisation for people living with energy limiting chronic illness. In response to the call for evidence by the Women and Equalities Committee, we conducted a survey between 15-24 April 2020 to ask about the impact of coronavirus and associated policies on people with chronic illness. The survey was open to anyone based in the UK living with at least one chronic condition. This evidence brief is based on 776 responses.

Evidence Summary

- There is a population who are at increased risk from coronavirus due to underlying chronic conditions but who are not included on the government’s highest risk list. These people’s needs are being ignored and their health and wellbeing is deteriorating.
- 28% of our survey respondents did not know if their chronic condition placed them at higher risk according to government guidance.
- 86% of respondents reported that the pandemic has had a negative impact on their ability to access food and essential supplies. Many of these people are largely housebound and rely on supermarket deliveries. They are now denied access because of overwhelming demand and unclear guidance. For example, although ME is a neurological condition, it is not specifically named in the guidance that shops and services are using to respond to the needs of

vulnerable customers. The current policy is depriving disabled people access to the essentials for survival.

- The overwhelming majority of our respondents were disabled women, who are already at greater risk of marginalisation and exclusion.
- Of the respondents under the regular care of a GP or specialist for chronic conditions, 66% reported disruption to care during the pandemic. This has long-term implications for people's health and will place increased pressure on the NHS and social care once the current crisis has passed.
- 56% of respondents reported that their health had got worse since the pandemic began, with a significant number reporting the detrimental impact of increased stress and anxiety.
- Many respondents reported experiences of discrimination and ableism in shops, the NHS, the media and public conversation. People reported feeling unseen, unheard and unvalued.

Survey Results

Respondents

| Respondents (Total N=776) | | % |
|--|--|----------|
| Age Group | | |
| | 18-30 | 7.35 |
| | 31-70 | 88.14 |
| | 70+ | 4.51 |
| Gender | | |
| | Women | 85.01 |
| | Men | 10.85 |
| | Other | 3.61 |
| Ethnicity | | |
| | White | 97 |
| | Other | 3 |
| Sexual Orientation | | |
| | Heterosexual Straight | 75.52 |
| | Bisexual | 10.16 |
| | Lesbian/ Gay Woman | 3.91 |
| | Gay Man | 1.30 |
| | Other | 9.12 |
| Region | | |
| | Greater London | 8.57 |
| | West Midlands | 4.68 |
| | East Midlands | 6.10 |
| | East of England | 7.53 |
| | North East | 4.55 |
| | North West | 7.79 |
| | South East | 16.49 |
| | South West | 16.23 |
| | Yorkshire & the Humber | 9.48 |
| | Scotland | 9.61 |
| | Northern Ireland | 4.68 |
| | Wales | 4.29 |
| Location | | |
| | City | 31.74 |
| | Town | 42.62 |
| | Village or smaller community | 25.65 |
| Employment Status | | |
| | Not in paid employment | 69.51 |
| | In paid employment (full or part-time) | 14.08 |
| | Student | 2.58 |
| Subjective Socioeconomic Status | | |
| | Comfortable (I don't have to worry about money) | 26.78 |
| | Managing (I can afford the essentials) | 57.57 |
| | Precarious (Not always able to cover basic monthly expenses) | 15.65 |

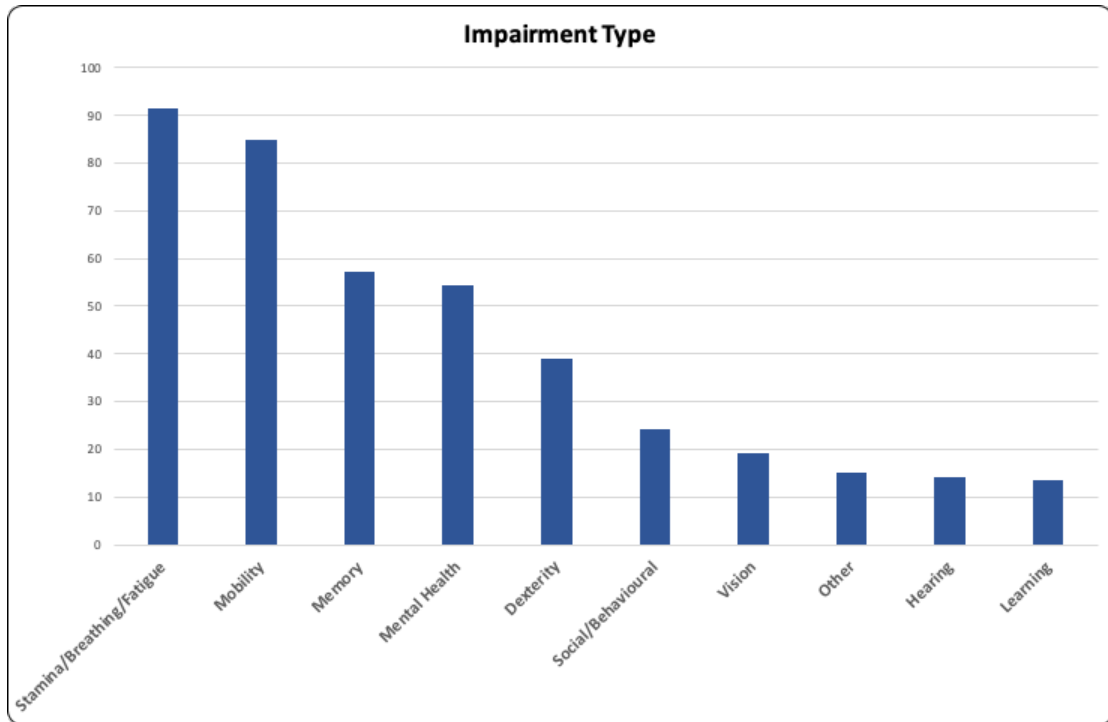


Fig 1. Percentage of survey respondents by impairment type (ONS categories). Respondents were asked to select all that applied.

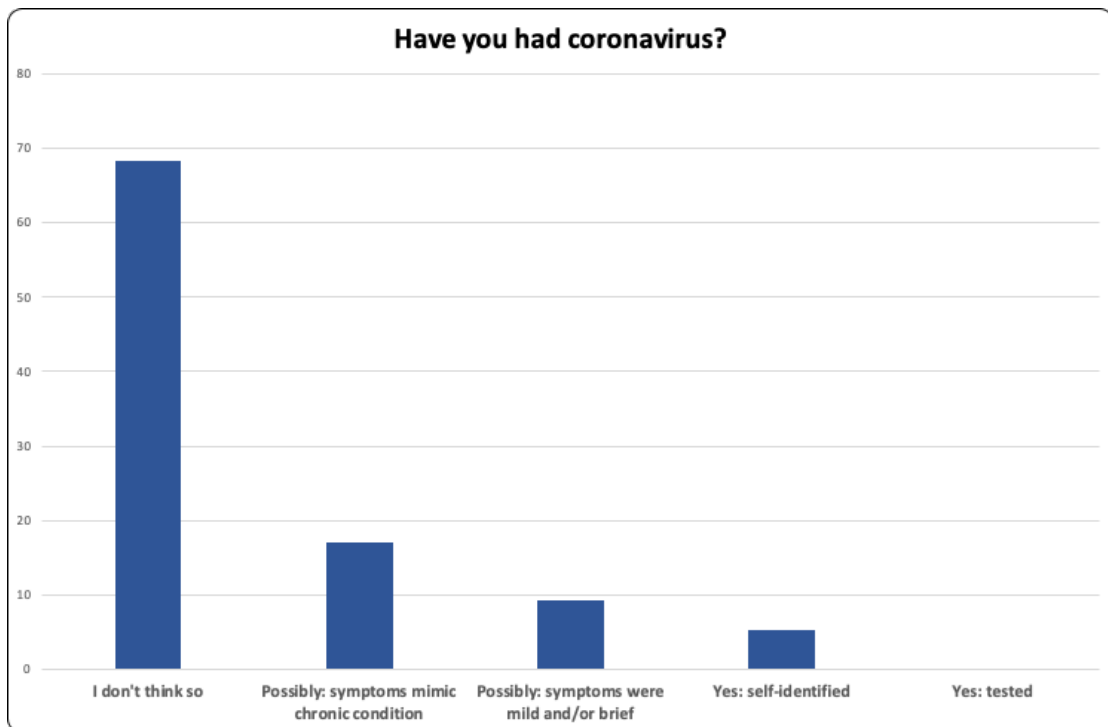


Fig 2. Percentage of people by coronavirus status.

- 17% of respondents reported that they had possibly had coronavirus but were unsure due to the close correlation of symptoms with those of their chronic condition/s.

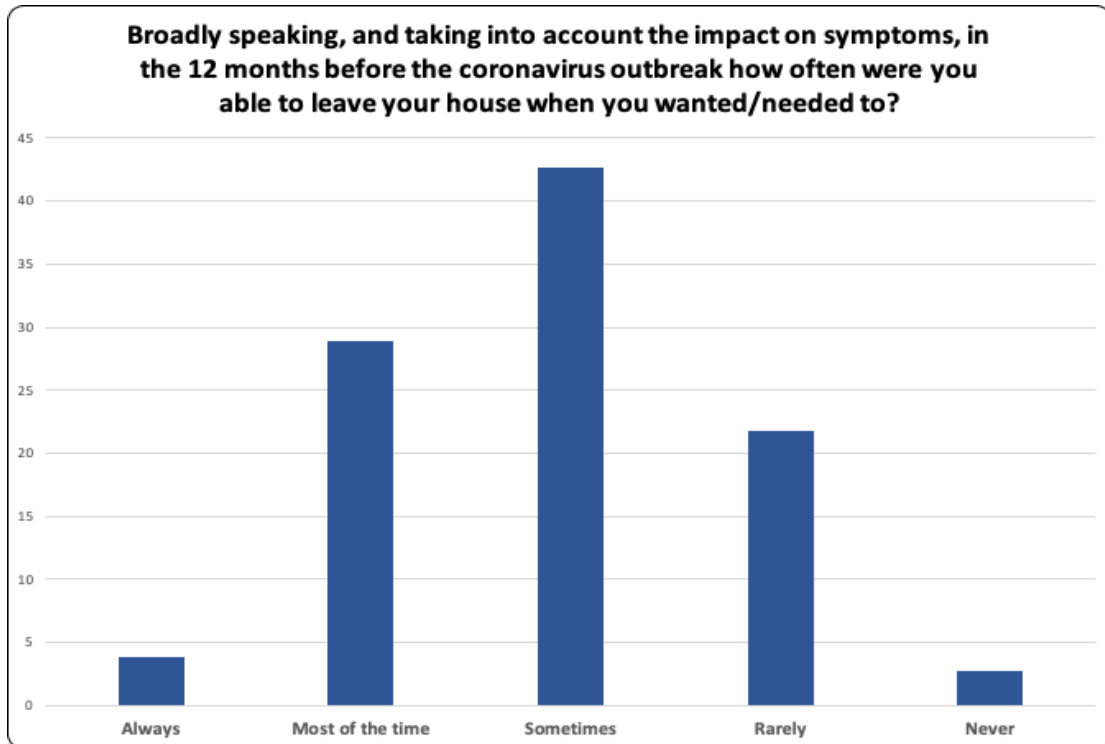


Fig 3. Percentage of respondents by ability to leave the house when wanted/needed.

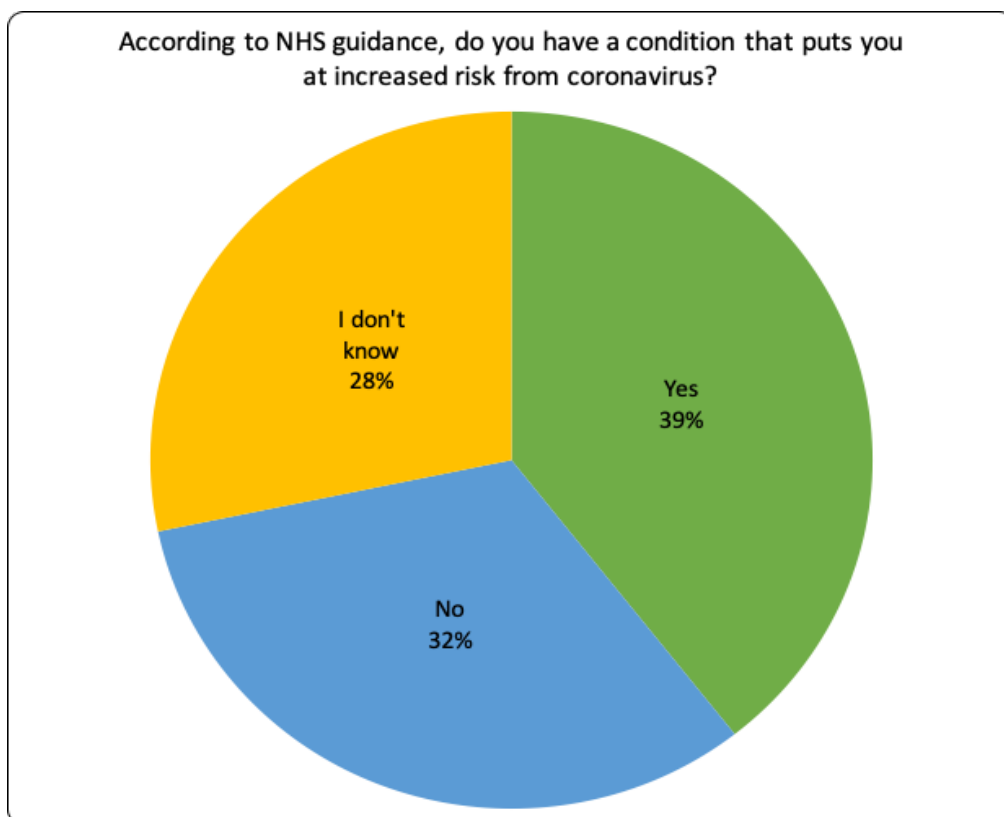


Fig 4. Percentage of respondents who self-reported their increased risk from coronavirus.

- 14% of respondents reported that the NHS had contacted them to confirm that they were in the highest risk group.
- 28% of people reported that they didn't know if their condition/s placed them at increased risk. This demonstrates the need for clearer guidance, both for people living with chronic conditions and the shops and services expected to respond to their needs.

Of those respondents under the regular care of a GP or specialist, 66% reported disrupted access to care since the pandemic began.

“There has been a major impact on the ability of people with severe chronic illnesses to access support and healthcare. I am extremely concerned about the backlog this is going to cause down the line, as there are already significant waiting times for specialists. The NHS has been underfunded for so long that I am terrified I won't have any access to this specialist care when the pandemic subsides. Our conditions are not going away and I think the lack of care during this time will cause irreversible damage to many of us and make our conditions even worse. I think policy makers have to understand that many people with chronic and rare diseases already feel like we are forgotten, but there are millions of us and this could cause a tsunami of healthcare problems after the pandemic earthquake.”

– **Woman in East Midlands, living with asthma, fibrous dysplasia, hypermobility syndrome.**

“Appointments I have fought for and waited almost a year for have been cancelled.”

– **Woman in South West England, living with myalgic encephalomyelitis (ME), postural orthostatic tachycardia syndrome (POTS), irritable bowel syndrome (IBS), ulcerative proctitis.**

“Diabetes nurse appointment cancelled, diabetes annual review cancelled including eye screening, endoscopy for Crohn's cancelled, asthma annual review cancelled. I used to have monthly GP review - cancelled, but I can contact by phone for emergency.”

– **Woman in East England, living with diabetes, Crohn's disease, asthma, endometriosis, post-traumatic stress disorder (PTSD).**

“Hospital appointments for pain injections, neurologist, infusions have all been cancelled.”

– **Woman in London living with spinal cord injury, chronic pain, neurogenic bladder and bowel, osteoporosis.**

“I have mental health therapy twice a week; this has been cancelled and nothing has been put in place. All specialist appointments that I've been waiting 9 months for have been cancelled or even discharged.”

– **Woman in South East England, living with ME, fibromyalgia, POTS, anxiety, depression, costochondritis, asthma, IBS, interstitial cystitis, non-alcoholic fatty liver disease (NAFLD).**

“I had a text saying not to contact them unless it's an emergency.”

– **Woman in Scotland, living with ME.**

“When I asked if I could check with the GP if I was in the vulnerable group I was told to look online.”

– **Woman in Yorkshire and the Humber, living with fibromyalgia.**

“I have sought medical support for infections but been unable to make contact with my medical surgery as my only way I can communicate is via email (I am too weak and disabled to use the telephone) and the surgery now only replies to telephone calls. I have no support and no one to telephone for me.”

– **Woman in South West England, living with severe sweating disorder, severe ME, multiple chemical sensitivity (MCS), spinal nerve disorder, complex PTSD.**

“The doctors are unable to grasp ‘don't phone me, I can't hear'. It's all so much harder.”

– **Woman in South West England, living with ME, rheumatoid arthritis (RA), hearing impairment.**

56% of respondents reported that their health had got worse since the lockdown began.

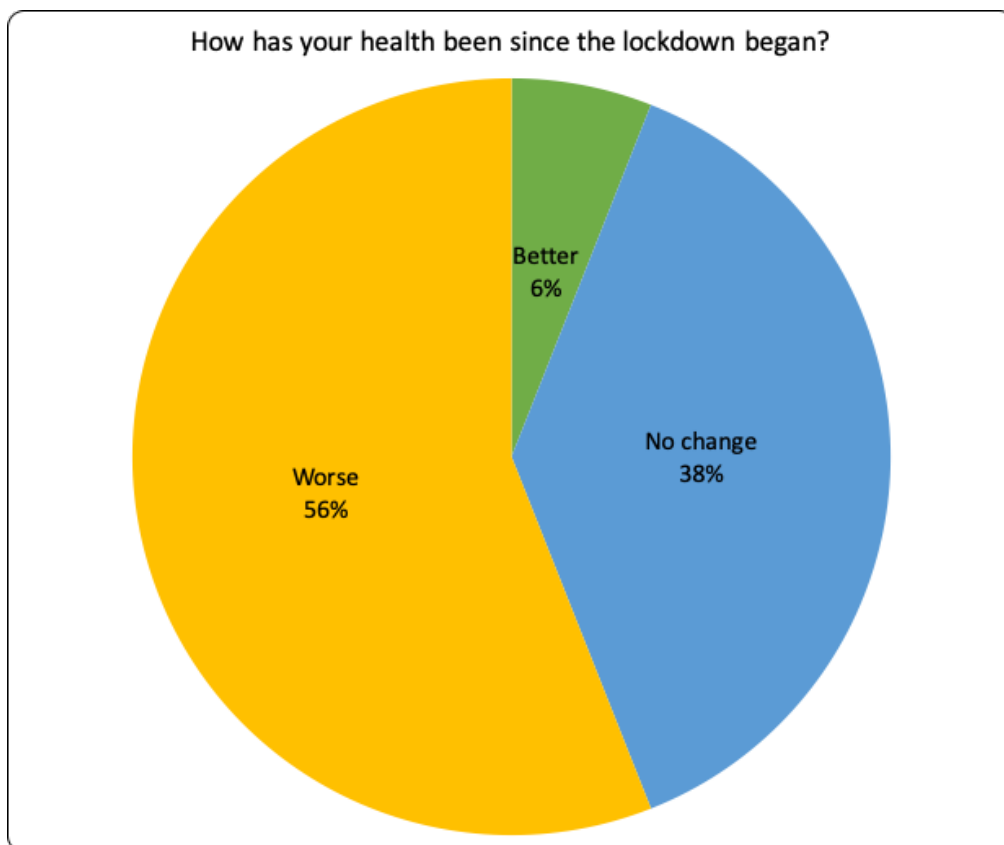


Fig 5. Respondents' self-reported health status since the lockdown began.

“Chronic pain and fatigue are through the roof due to me no longer having help from carers and having to somehow manage alone. IBS has flared up badly due to problems accessing food.”

– **Woman in North East England, living with sitting disability, chronic pain, IBS, PTSD.**

“Constant stress trying to get food has caused increase in symptoms.”

– **Woman in Scotland, living with ME, peripheral neuropathy, osteoporosis, arthritis, PTSD.**

“Mood much lower, pain worse, lack of exercise means joints dislocate more often and I end up bedridden. I can't see a chiropractor to pop my joints back in.”

– **Woman in South West England, living with Ehlers Danlos Syndrome, fibromyalgia, slipped discs, dislocating joints.**

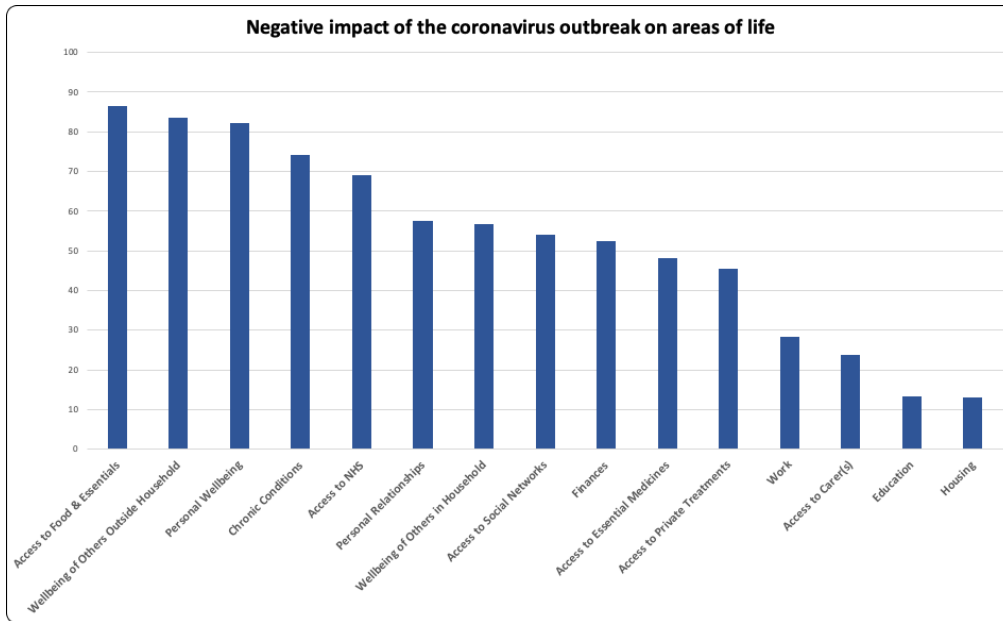


Fig 6. Percentage of respondents who reported that the pandemic has had a slightly to significantly negative impact on specific areas of life.

82% of people reported that the pandemic has had a negative impact on their overall wellbeing.

“I seem to be in a category where I'm not vulnerable enough to get help with essentials like food shopping, but too vulnerable to catch covid and survive.”

– **Woman in Wales, living with fibromyalgia and stenosis of the spine.**

“The lack of access to medical help for anything other than coronavirus is very scary. Plus, if I get the virus will they decide I'm not worth saving because of my conditions?”

– **Woman in North West England, living with Graves' disease, thyroid eye disease, anxiety disorder, depression.**

“I'm on the 'vulnerable' list but not the 'extremely vulnerable' list - I am concerned about the possible effects of coronavirus on me but there is no support available with things like shopping. As a younger person with no visible disability I fear I wouldn't be allowed to use shopping hours dedicated to vulnerable people.”

– **Woman in London, living with ME.**

86% of people reported that the pandemic has had a negative impact on their access to food and essential supplies.

“We have lost both our incomes, and we were already using foodbanks before the lockdown. We can't access them now, and nobody has been in touch from the various services that were in contact with us. I am very concerned about accessing food as I cannot stand for long at all and queuing would be out of the question at supermarkets.”

– **Woman in Scotland, living with fibromyalgia.**

“I am housebound and one of the forgotten ones. I feel very isolated, frightened, anxious, lonely, hungry, very tired, hopeless. I am hungry due to the fact I need home delivery groceries and it's a three-week wait. I am nearly down to my last scrap of food from my freezer and I don't know what I am going to do. I sleep a lot lately, very tired probably because of my high dose of medications and very little food.”

– **Woman in Northern Ireland, living with arthritis, complex regional pain syndrome (CRPS), dystonia, fibromyalgia, degenerative disc disease (DDD), heart condition.**

“The stress of trying to get food has interrupted sleep and now I am crashing...loss of energy, lots of pain...having to rest 80% of the day and skipping meals as too exhausted.”

– **Woman in Wales, living with ME.**

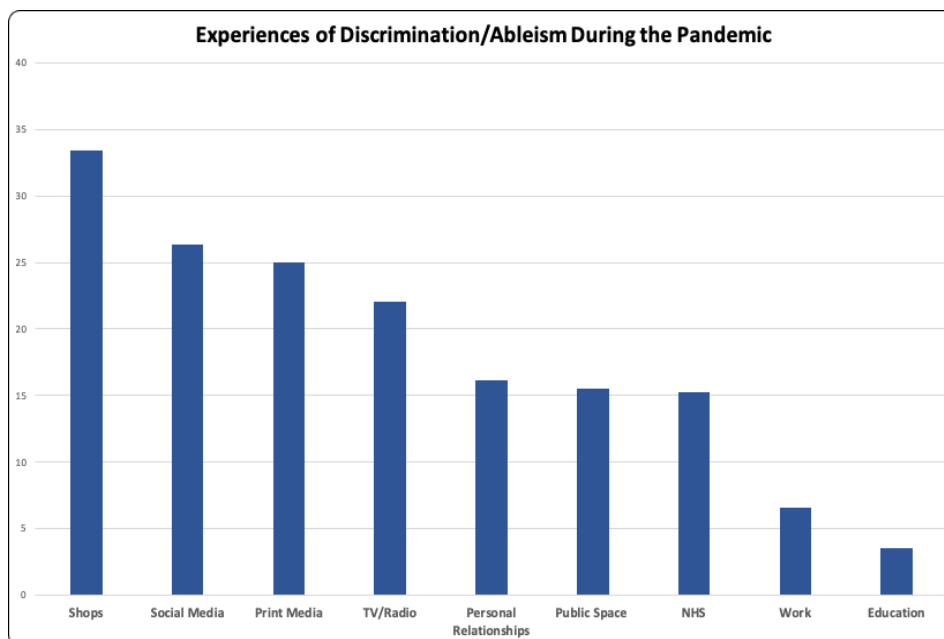


Fig 7. Percentage of respondents reporting experiences of discrimination/ableism in different domains.

“I was very upset to see that because I need a carer, the NHS considers me too frail for ventilation and my life not worth saving. Hard to live with this hideous, soul-crushing disease knowing the NHS doesn’t consider me worth saving. Not sure I’ll ever trust the NHS again.”

– **Woman in London, living with ME.**

“I feel the whole 'management' of the pandemic by central & local governments has been discriminatory as we have been completely overlooked.”

– **Woman in East Midlands, living with fibromyalgia, Sjogren’s syndrome, osteoarthritis, spondylitis, sleep apnea, depression, disassociation disorder, PTSD.**

“When I told the supermarkets how I rely on delivery to get basics, they responded with script about the government’s ridiculously limited list of vulnerable groups each time. I was completely brushed aside.”

– **Woman in East Midlands, living with ME, polycystic ovary syndrome (PCOS), IBS.**

“I do feel that I have been rendered more 'invisible' than usual by the situation. I feel vulnerable due to my health conditions, but it is hard to get food and essentials delivered, as I am not in the 'most at risk' category. I am protecting myself, but I don't feel protected, except by my local pharmacy, which delivered my prescription medicines.”

– **Woman in East England, living with costochondritis, chronic cough, type 2 diabetes, high blood pressure.**

“It has been incredibly difficult to prove you are disabled because people apply old-fashioned criteria of what is a disability to police access to things like supermarkets.”

– **Woman in East Midlands, living with asthma, fibrous dysplasia, hypermobility syndrome.**

“I stopped in park for a rest and was shouted at for stopping. It made me anxious to go out again.”

– **Woman in East Midlands, living with ADHD, dyspraxia, PTSD, IBS, chronic pain.**

“I feel a bit like the experiences of disabled and chronically ill people have been at once co-opted and erased. We are experts in isolation yet we've been ignored/told we are expendable.”

– **Woman in Scotland, living with fibromyalgia, c-PTSD, PCOS, Hashimoto's disease.**

“Politicians not talking to, but talking about, disabled people (when they remember us) has been quite painful to experience. The 'oh, it only kills people with a pre-existing condition,' as though that doesn't include anyone they think is listening. It's never 'your life is valuable and we're doing all we can to support you' - it's often in the third person.”

– **Woman in East England, living with a thyroid condition.**

“The marginalisation of people whose disabilities makes them literally the most vulnerable to a novel virus is richly ironic. I have particularly experienced this in work/educational settings: for instance where concern is expressed 'for those whose loved ones and family may be more vulnerable', rather than those who may be more vulnerable themselves.”

– **Woman in London, living with Behcet's disease.**

Conclusions

We recommend that the following conclusions be considered by the government when reviewing its policy response to the coronavirus pandemic.

- There is a population at increased risk from coronavirus due to underlying chronic conditions but who are not included on the government's highest risk list. These people's needs are being ignored and their health and wellbeing is deteriorating.
- Overall wellbeing and access to food and essential supplies were the areas that respondents reported had been most negatively impacted by the pandemic.
- The pandemic has already had a significant impact on access to GP and specialist care for the majority of our respondents. This has long-term implications for people's health and will place increased pressure on the NHS and social care once the current crisis has passed.
- The lack of clear and consistent guidance about underlying conditions is preventing people with chronic conditions accessing essentials for survival.

Note on evidence limitations

While this report sheds crucial light on the significant challenges faced by people living with chronic illness during the coronavirus pandemic, we have focused on headline findings given the timeframe available. The survey has yielded a rich data set that deserves deeper analysis in slower time. There are two further key limitations of the exercise. First, the respondents were from an overwhelmingly white ethnic background. This constrains our ability to conduct the intersectional analysis that is critical to more deeply understanding the unequal impact of the pandemic on black and ethnic minority people living with underlying health conditions. Second, we disseminated the survey primarily through the CIIP mailing list and Twitter and it was only open for a short period. The responses therefore represent people with existing access to those networks, and who were well enough to complete the survey in the time available. For these reasons, we cannot generalise these results to people with chronic illness who are the most socioeconomically marginalised, and we can be confident that this report reveals only the tip of the iceberg when it comes to the lives of disabled people during the pandemic.

Acknowledgements

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