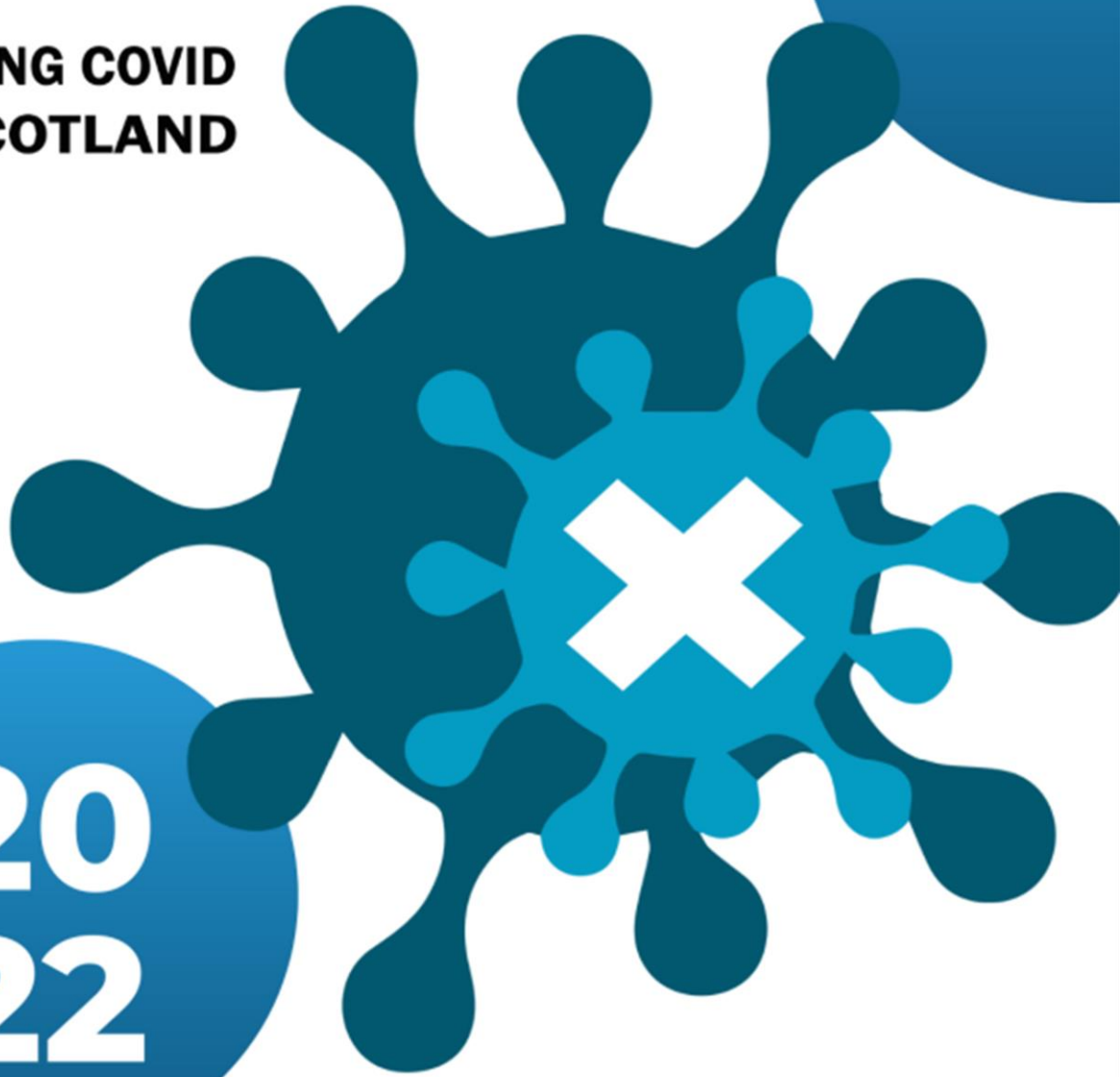




**LONG COVID  
SCOTLAND**



**20  
22**

# ***Hearing our Voices***

*Long Covid: The impact on our lives*



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## ACKNOWLEDGEMENTS

We wish to thank all participants for their valuable contributions, including people with long COVID and Scotland's academic community. Thank you for your patience, for comments, feedback and your participation in focus groups. We especially want to thank the 222 participants living with long COVID who put so much of themselves into completing the questionnaire.

This report is a piece of co-produced citizen research. Designed, analysed, and written by people living with long COVID. While some of us may have research experience, this is limited and none of us are professional researchers.

The report also received no funding. Over the last two years, grassroots, patient-led groups have taken the lead in shouting loud and raising awareness of long COVID. Predominantly with no funding support from those structures and organisations that hold power.

## Authors

**Lead Author:** Chris White

**Co Authors:** Jenny O'Boyle, Jane Ormerod and Risga Summers

All Authors are living with Long COVID and volunteers at Long Covid Scotland.

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## Introduction

This report is written by members of Long Covid Scotland. An action group, led by and for people with long COVID. We advocate for treatment, rehabilitation, research and recognition for people living with long COVID in Scotland. In March 2022, we approached the second anniversary of the COVID-19 Pandemic. We asked our members living with long COVID to share their experiences of long COVID and how it changed their lives. We wanted to capture meaningful narratives carrying authenticity and power in a way that is difficult to capture in academic studies and clinical data.

In early 2020 the first cases of COVID-19 were reported in the UK. Quickly, concerns were raised about the spread of this new infection, its severe health risks, the rising numbers of people hospitalised, particularly in intensive care units, and loss of life for many people. Despite the high number of people hospitalised, Government advisors said there was an expectation that most people would experience milder symptoms and could expect a full recovery. However, by the summer of 2020, people started to report longer-term health problems impacting their daily lives. As numbers increased, the term long COVID became widely used to describe these experiences of longer-term illness.

Long COVID is defined by the World Health Organization as a condition that occurs in individuals (adults and children) with a history of probable or confirmed SARS CoV-2 infection. Diagnosis is usually three months after the onset of COVID-19, with symptoms that last for at least two months and cannot be explained by an alternative diagnosis<sup>1</sup>.

We now understand that long COVID can affect multiple organs and systems within the body, including respiratory, cardiovascular, neurological, gastrointestinal, and musculoskeletal systems. Common symptoms include fatigue, breathlessness, and cognitive dysfunction. Symptoms may also be new following initial recovery from illness. People experience fluctuations and relapses of symptoms that majorly affect everyday life.

We need to recognise that the people most impacted by an illness often struggle to have their stories heard, validated, and understood. 225 people responded to our questionnaire, including parents of children and young people suffering from long COVID. Some of those direct messages are included in this report. This report is made up of the voices of people living across Scotland from varying backgrounds wanting their voices to be heard.

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<sup>1</sup>[https://aci.health.nsw.gov.au/\\_\\_data/assets/pdf\\_file/0011/726878/ACI-CPG-for-assessment-and-management-of-adults-with-post-acute-sequelae-of-COVID-19.pdf](https://aci.health.nsw.gov.au/__data/assets/pdf_file/0011/726878/ACI-CPG-for-assessment-and-management-of-adults-with-post-acute-sequelae-of-COVID-19.pdf)

## Methodology

### Purpose

Long Covid Scotland aims to understand how long COVID has affected our lives. The impact on our health and wellbeing and how it has affected our relationships with family and friends, healthcare professionals and employers. We hope to use this learning to influence policymakers, researchers, health and social providers and the Scottish Government to develop better support for people living with long COVID.

### Design

Long Covid Scotland recognises the importance of co-produced, lived experience citizen research. We invited members to discuss the questionnaire design to effectively evaluate the impact that long COVID was having on people's lives. This identified several areas to explore. How did people experience illness? Were they tested for COVID-19? What symptoms do people experience? What has been their experience of healthcare services, and what are the broader impacts of adjusting to a long-term condition?

People felt it was essential to gather some baseline information but allow people plenty of space for self-expression encouraging a qualitative narrative of how long COVID affects their lives. We circulated a draft for comments from members of Long Covid Scotland and academics with whom we had a working relationship. Following this peer review, that questionnaire underwent several changes and adaptations before being released as an online questionnaire and promoted on social media.

Recognising the questionnaire was long, we suggested people complete the questionnaire in stages to avoid fatigue. The questionnaire was open for four weeks in March 2022. A total of 225 people responded to the online questionnaire. Three people did not complete the questionnaire as they lived outside of Scotland, and 222 people completed the questionnaire.

Demographic information was collected from participants, and people responded from most local authorities in Scotland, covering a wide age range. No personal identifying information was collected to protect anonymity, and participants were informed that this would be removed should they include any easily identifiable information.

### Analysis

Long Covid Scotland asked for volunteers from the group to take part in the analysis and write-up of the final report. Taking a thematic approach, each volunteer took a section of the questionnaire to do a first analysis.

With 222 responses, including a large amount of free text, there has been much information to read. Throughout the process, it has been essential to let the personal voices come through in identifying themes and developing the narrative of how we experience long COVID in Scotland

## What is Long COVID?

Long COVID refers to a prolonged and debilitating illness where symptoms continue long after contracting the COVID-19 virus. There are more than 50 symptoms associated with long COVID. Common symptoms include fatigue, breathlessness, and cognitive dysfunction (for example, confusion, forgetfulness, or a lack of mental focus and clarity). These symptoms might persist from their initial illness or develop after initial recovery from COVID-19. Symptoms can come and go with people often reporting relapses over time.

Dr Anthony Fauci suggests a staggering 25-35% of people with a Coronavirus infection will develop Long COVID. The Office of National Statistics estimates that 2,3 million people in the UK are living with the condition, which means over 175,000 people in Scotland are likely to have long COVID.

### People with Long COVID can experience the following:

- **Severe and profound symptoms.** Long COVID can affect the entire body. Cases vary greatly, with symptoms including but not limited to breathing difficulties, chest pain, numbness, fatigue, tachycardia, and allergies. The effects on daily life are considerable.
- **Psychological trauma.** Experiencing a severe infectious disease, followed by further prolonged illness can lead to complex trauma affecting a person's mental health. Understandably, people are reluctant to ask for help, especially if their physical symptoms have been misdiagnosed or misunderstood.
- **Issues around working, studying and being a carer.** Many with long COVID cannot work, study or carry out caring responsibilities. Those who have been able to return to work, study or care often push through out of necessity. Some people struggle with returning to employment or education due to a lack of support and understanding of the condition from employers, lecturers and support staff.
- **Financial problems.** Many with long COVID experience financial difficulties due to being unable to work and/or paying for private investigations, health insurance and complementary therapies. Despite meeting the criteria, some are refused disability benefits, such as Personal Independent Payments.
- **Stigma and discrimination.** People with long COVID can feel discriminated against. This can be due to misconceptions about long COVID, not being hospitalised, or contracting COVID-19 before testing was in place. Pre-existing inequities such as socioeconomic status, race and gender may also add to the experience of stigma. This is worsened by health practitioners and researchers seemingly having more power and authority than patients and carers.

## Hearing our Voices

### Long COVID: The Impact on our lives

***“Despite gargantuan efforts, the voices of lived experience are not being heard at local or national levels. This includes from Scottish Government, CHSS and health practitioners. This has had the biggest impact on both my physical and mental health.”***

*Participant - Long Covid Scotland Survey, Spring 2022*

In Oct 2022, the Office of National Statistics (ONS) estimated that 2.3 million people (3.5% of the population in the UK) self-reported long COVID symptoms. Proportionally this could mean at least 175,000 people in Scotland are living with long COVID. Almost three-quarters (73%) of people reported symptoms lasting at least 12 weeks and nearly half (44%) had symptoms more than a year after first becoming unwell.

We recognised that asking people living with long COVID to complete a lengthy survey can add to the fatigue they experience. But we felt it was important to give people an opportunity to say what was most important for them about the experience of long COVID.

The opening question invited people to say, in their own words, what was most important to them? 172 people answered this, from a total of 252 respondents. From these statements, we have been able to draw out common themes, building a narrative of long COVID.

In this section, we outline the most significant emerging themes and the devastating impact long COVID has had on people’s daily life. This covers all aspects of their health, including mental, physical and emotional health, followed by the effects on working life, family life, relationships and social lives. People report that the misunderstood and chronic nature of this illness exacerbated the lack of understanding and dedicated care. They highlighted the lack of treatment, support and information. This reinforces the need for more resources to educate GPs and medical specialists.

We believe that such education should be based on emerging research evidence and the experience of people living with long COVID.

**Demoralised by illness:** Long COVID's impact on people's lives cannot be ignored or underestimated. People commonly talk about how the devastating and debilitating symptoms of long COVID affect their quality of life. The lack of treatment, adjusting to the uncertainty, worries for the future, and the lack of understanding and support have made people feel demoralised and disheartened as they face an uncertain future.

*“It has devastated my life in all areas. I feel unsupported by the medical and welfare communities. It has been a heart-breaking battle to receive any assistance. I have been unable to return to work since becoming unwell in March 2020.”*

**Impact on our working lives:** Many people living with long COVID of working age were employed before the pandemic. Illness has led to long-term sick leave, reductions in income, reduced working hours, and many leaving employment altogether. Where people have been able to return to work, employers have needed to make adjustments to provide additional support, which for smaller employers can be costly.

*“I’m lucky I’ve been able to return and that I got sick pay. But it is very difficult fitting work back into a life that is changed beyond recognition. I am up to 15 hours a week as part of a very phased return and on the brink of relapse daily”*

**The impact on family life and relationships:** When someone has long COVID, it significantly affects other household members and the broader family. We hear people talk about how illness has changed family life. How they cannot tidy the house, do things with their children, or enjoy leisure activities. Added to this were emotional pressures, strains on relationships and dealing with financial pressures, particularly if work has been affected.

*I went from being a very active Mum of two, running my own business, to barely able to leave my house. Long COVID has impacted so much of my life. I had to shut my business down, couldn't do any active things that I previously enjoyed, and couldn't even do normal jobs around the house for a very long time. It affected my mental health, but more so the mental health of one of my children, who wanted real Mummy back.”*



**Long COVID affects children:** There is still an incorrect belief that children are mainly unaffected by Covid. However, evidence is increasingly showing that many children with symptomatic and asymptomatic COVID-19 experience long-term effects months after the initial infection<sup>2</sup>. We have heard parents describing the devastating impact on their children and the frustration among parents of the lack of support from doctors or education services.

*“She is now unable to attend school in person due to her symptoms. She is now unable to access online school due to the cognitive and Neuropsychiatric symptoms which have completely disabled her ....., 2 years in and we’ve only had one CAMHS appointment and 2 physio appointments or simply inaccessible. There is nothing for children.”*

*View from a parent*

**Experiences of long COVID can lead to social stigma:** Public attitudes toward long COVID remain ambiguous. Misconceptions or misrepresentations of people living with long COVID have led to many people experiencing social stigma and discriminatory behaviours. This can lead to feelings of isolation, stress and anger for people living with long COVID.

*“It’s also been a complete eye-opener with regards to the behaviour of family, friends and the U.K. public. It has caused me very much stress, frustration and sheer anger at the refusal of people to get vaccinated and the ‘it’s just a cold’ brigade.”*

**A need for better public health messaging:** People with long COVID have been demoralised by poor Public Health messaging. The belief still exists that COVID-19 is mainly a short-term respiratory, flu-like illness. There is a need to address the belief that only people with underlying health conditions can experience long COVID and that anyone can develop long COVID.

*“The community at large remain unaware of long COVID, and this is worrying, I feel let down by the Government who show no urgency in providing help”*

*“Do they even believe me? ‘You look great!’ they say. I’m a single parent so the only income I have is my income. I can’t do things with my son, and it breaks my heart. I feel so guilty. I have felt so alone at times.*

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<sup>2</sup> Attributes and predictors of Long-COVID: analysis of COVID cases and their symptoms collected by the Covid Symptoms Study App Carole H. Sudre et al doi: <https://doi.org/10.1101/2020.10.19.20214494>

**Living with a myriad of unpredictable symptoms:** Long COVID presents as an extensive and “perplexing mixture of symptoms.” These can last months after having a confirmed or suspected case of COVID-19. Symptoms can affect your whole system, with symptoms coming and going, new symptoms developing, and people experiencing unpredictable fluctuations and relapses over time with no real treatment plan.

*"So many bewildering symptoms. You may get used to one kind of group of symptoms and how to manage them, when others pop up. There are so many layers to this condition. Debilitating, depressing - it's a very lonely condition"*

**Recognising the chronic nature of long COVID:** Long COVID is a complex multi-system, long-term, and life-changing illness. There is no known cure or commonly understood sickness duration; however, research suggests that it can last for months or even years<sup>3</sup>. Some people have not recovered two years after the pandemic's start. These people carry the longest burden of illness, many of whom continued to provide essential frontline services after lockdown restrictions were announced.

*"I will be 2 years in on 14 March. I know this is a new virus but to still not have a treatment plan in place or any idea of whether I will recover fully - it's not acceptable. I feel I have been abandoned by the medical profession, even where they have been sympathetic".*

**The problem accessing care and treatment through their GP:** People with Long COVID often report frustration at accessing care and treatment through GP practices. It can feel like a lottery whether their GPs understand long COVID, with many people saying that they felt let down by their GP practice.

*"My GP has no answers. Test after test after test - normal; 'so that's reassuring' they say. Is it? Feeling like this but there's no apparent cause? Like I am having a heart attack? I'm terrified, not reassured."*

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<sup>3</sup> National Institute for Health and Care Research (NIHR), 2020

**Increasing GP understanding:** In Scotland, the current healthcare pathway for long COVID treatment is through the patient's GP and Primary Care services. There is a need to improve understanding of long COVID and develop more robust treatment pathways, including improving access to hospital-based specialist services.

*“Long COVID feels progressive and totally debilitating, and a life-changing illness. Clinicians and GPs in Scotland need more training to support us”*

**A systematic approach to investigations:** Currently, there is no objective diagnostic test for people with long COVID. This can be problematic, particularly for long-haulers who may not have had a positive COVID-19 test result to receive a diagnosis. Repeatedly we heard people saying that clinical tests they had been sent for were inconclusive or showing results within a normal range, causing patients to question whether they were being believed.

*“It is important that GPs and medical practitioners are very aware of LC and all its varieties of presentation and effects on organs and that the basic tests do not show its existence but that it is a real physical response to having had the virus. It may be invisible in some tests, but it is there. No one wants to prolong illness.”*

**Improving care and treatment pathways:** The multi-systemic nature of long COVID requires thorough investigation and access to appropriate specialist services. However, very few people said they received ongoing specialist care and treatment. There is a need for all patients to receive a long COVID holistic assessment of their physical, cognitive, psychological and functional abilities so that they can be referred to the right specialist help.

*“Lack of referral pathways in the healthcare system. My GP tried to refer me to cardiology, respiratory and infectious diseases but they were refused because I am non-hospitalised long COVID. To get referrals taken I had to get on the front page of a national newspaper then referrals were magically accepted and fast-tracked.”*

**Exploring the value of alternative therapies:** Many people have found support in various alternative therapies accessed privately, often not offered or prescribed by the NHS. People have reported the positive benefits of alternative and holistic treatments on their symptoms and well-being. However, there are also concerns that people can become victims of ineffective or dangerous remedies promoted through the internet out of desperation.

*“I discovered a treatment that helps- oxygen therapy. Not one of the many clinicians I've seen even mentioned it, not even the ME/CFS clinic. ‘Not enough evidence to support it’. Mindfulness does not work for me yet was repeatedly pushed as if a cure for everything. At times I feel I've been blamed for not getting better. That I'm not trying hard enough. Not explicitly, but subtly.”*

**Let down and disappointed:** Many people with long COVID have expressed dissatisfaction with the Scottish Government's response to long COVID. Many of the people we heard from expressed dissatisfaction, abandonment, and feeling unsupported and unheard by the Scottish Government.

*"I sit at home all day wondering 'who cares! This is an international issue. Why are those suffering having to fight so hard to be heard, the medical community and Government should be driving this. It could be any one of them who suffers this awful condition next. Some days I wonder how I can go on existing like this and wonder if any one of those lucky to have avoided long COVID after their infection would like to walk in the shoes of any one of us suffering from it for even a day".*

## Our Experiences Contracting COVID 19

Coronavirus (COVID-19) appeared in Scotland and across the UK in early 2020, and by March, cases were recorded across all four regions in the UK, with the first COVID-19 UK death recorded on 7 March. On 23 March 2020, Boris Johnson announced that the government would introduce a nationwide lockdown, telling people they must stay at home and should only leave for essential reasons such as buying food and exercising once daily.

Early advice from the UK Government was that infection would result in a mild, short-term illness for most people. At this point, people were also told not to contact the health services unless absolutely necessary.

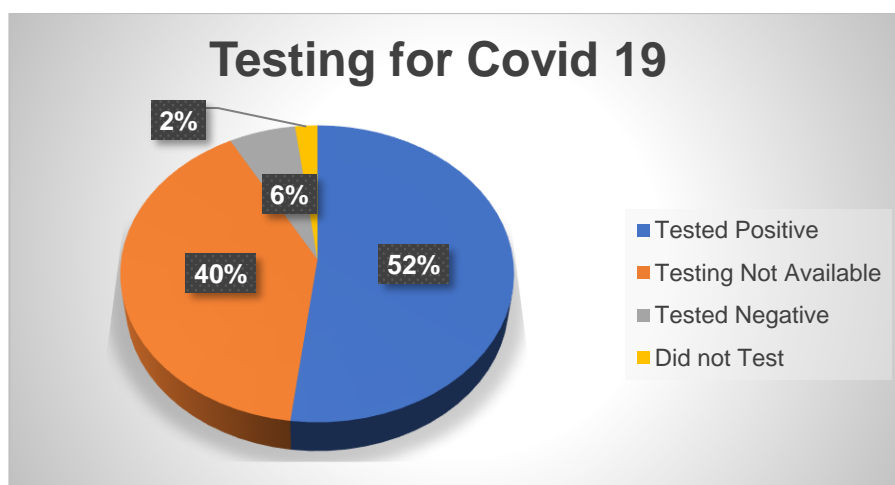
So far, there have been four Covid-19 waves in the UK. Two between March 2020 and May 2021, a third wave beginning in July 2021 and a fourth wave appearing in December 2021.

But it wasn't until August/September 2020 that community testing was rolled out across Scotland. Until then, testing was only available to people who were seen in the hospital.

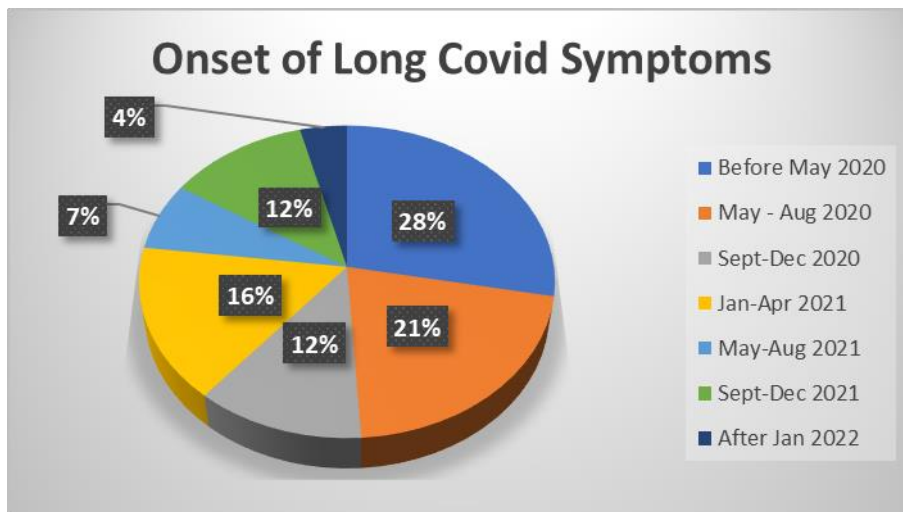
The introduction of community testing is a pivotal point in the long-covid story. People contracting Covid-19 in the first wave and going on to experience long-term symptoms often have no proof that they were infected. As a result, they frequently report problems with healthcare professionals not recognising that they may have long-covid.

*“People with Long COVID from March 2020, mostly did not fall into the 'at risk age groups' determined at the time, and were unable to be triaged properly face to face, despite having symptoms which would now enable them to be seen at hospitals”*

In our survey, 52% of people living with long COVID said they had tested positive for COVID-19, but 40% said testing was not available to them when they first developed COVID-19 symptoms. Of people who developed long COVID, 6% said they tested negative, and another 2% reported being asymptomatic for the virus.

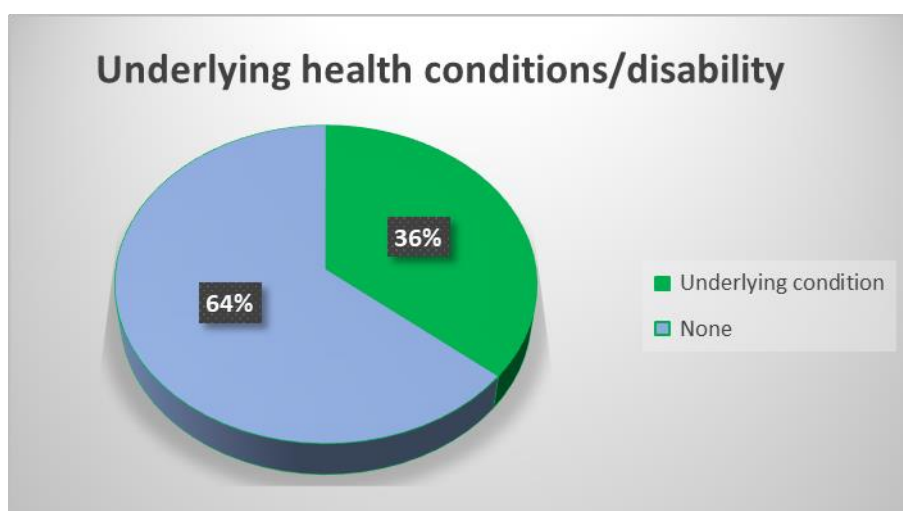


When asked when they first started experiencing the symptoms of their long-COVID, 49% of people reported developing long-COVID symptoms before September 2020; therefore, during the first wave and before community testing was widely available across Scotland.



During the second wave, between September 2020 and April 2021, 28% of people report developing symptoms, with 19% of people reporting noticing their symptoms during the second wave. There was a third virus wave between May and December 2021, with 19% of people believing this was when their symptoms began.

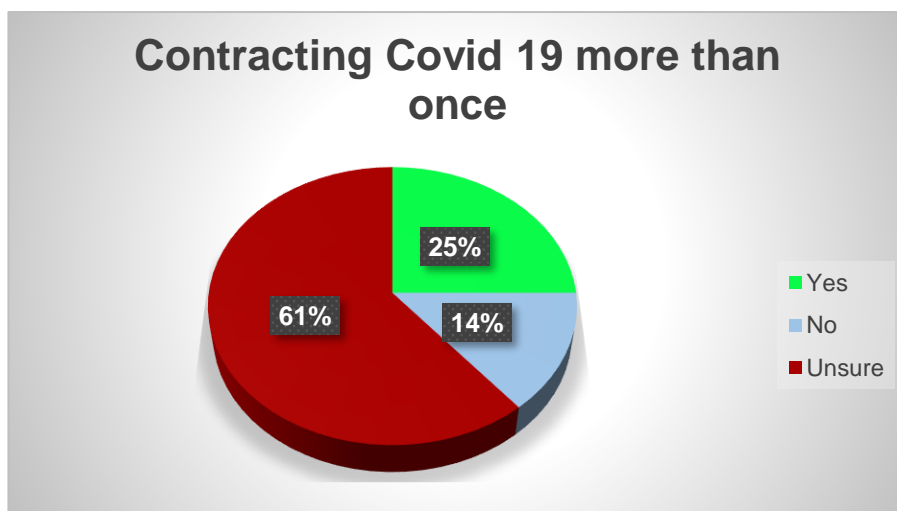
We expect that most of these people in this second and third wave had a positive test result at some stage. The survey was conducted throughout March 2022, but unsurprisingly there is an emerging new wave of people reporting ongoing symptoms associated with long COVID.



The media, anti-vax campaigners and poor public health messaging have created a myth that only people with underlying health conditions or disabilities are affected by long-COVID. We know from the many personal accounts that long COVID has destroyed the lives of people who previously had healthy and active lives before contracting COVID-19. In the survey, almost two-thirds (66%) of people reported that they had no underlying health condition or disability before contracting COVID-19.

*“Long COVID has affected every part of my life for the worse. From being a fit & healthy professional geologist working around the world, an ultra-runner, with an active social life and a regular volunteer, I was too ill to work at all for over a year, and I'm now only well enough to work half time from home, my income has reduced, and my long term employment depends on my employer continuing to enable me to work remotely, which I have no guarantee of. “*

People living with long COVID are concerned about contracting coronavirus again and how reinfections will affect them. Just under 1 in 4 people (24.8) said they had contracted COVID-19 more than once, and another 14% were unsure if they'd had COVID-19 more than once.

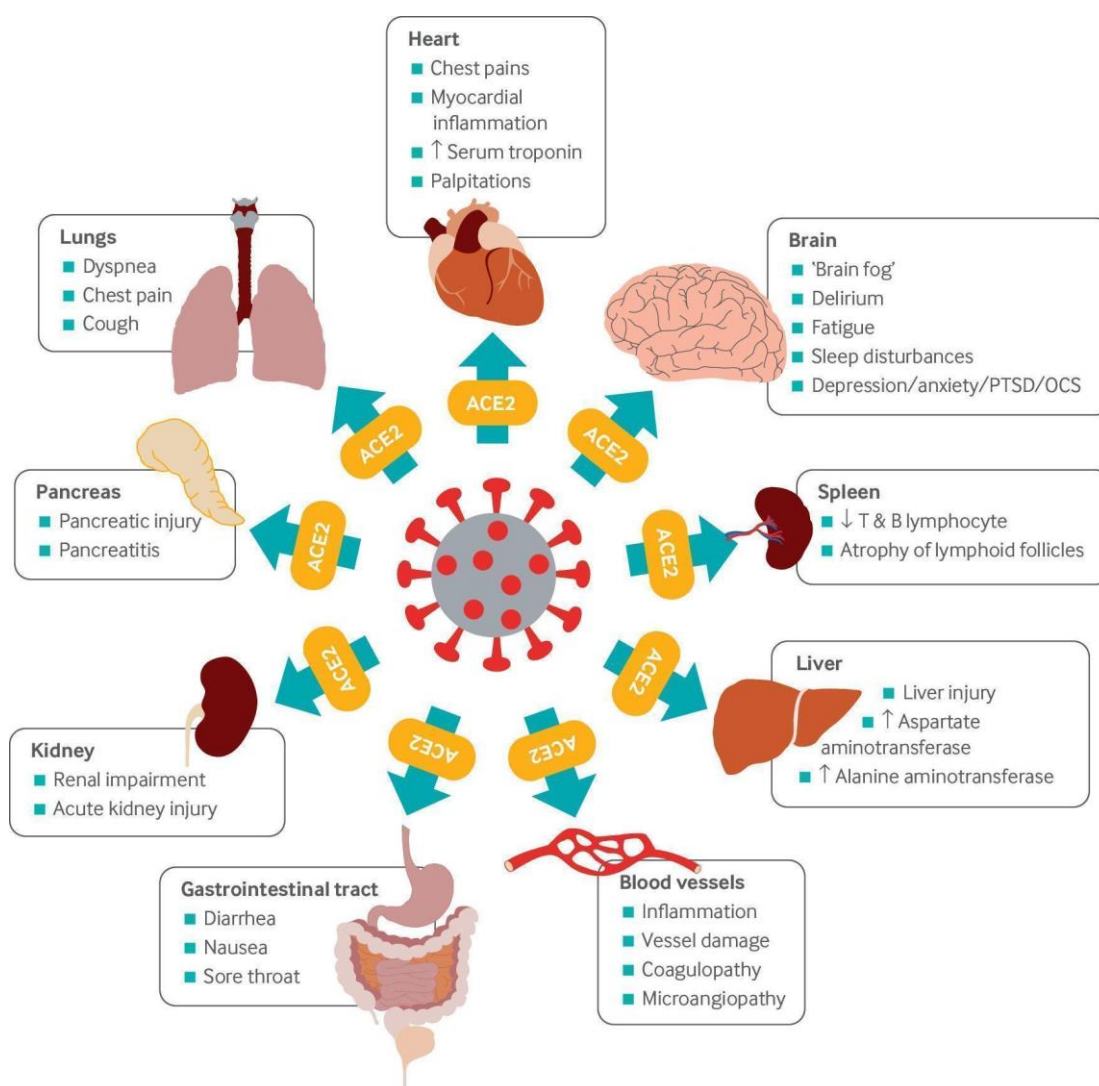


## Our Experience of Long COVID symptoms

People living with long COVID reported a wide range of cyclical or constant and multi-systemic symptoms, leaving them disabled and debilitated.

Commonly, people reported breathlessness, fatigue, cognitive impairments, chest pains, palpitations, joint and muscle pains, sleep problems, skin conditions, upset stomachs and diarrhea, altered sense of taste and smell.

Symptoms often fluctuate and vary in severity, with people reporting that cognitive exertion or physical activity, infections and stress seem to have a negative impact on the severity of the symptoms they were experiencing. As a multi-system illness, symptoms can manifest anywhere in the body<sup>4</sup>.



<sup>4</sup> Long Covid—Mechanisms, Risk factors, and Management *BMJ* 2021; 374

doi: <https://doi.org/10.1136/bmj.n1648> (Published 26 July 2021) cite: *BMJ* 2021;374:n1648 Crook et al



The relapse and remitting nature of system-wide symptoms can cause confusion and misunderstanding, adding to the invalidation for people living with long COVID.

The symptoms people experience also seem to change over time, with some highly persistent symptoms, such as breathlessness, fatigue, and cognitive impairments. Other symptoms appear to ebb and flow, with some symptoms disappearing over time or people experiencing new symptoms at varying stages of their illness.

The experience of trying to understand and manage a myriad of complicated and fluctuating physical symptoms severely affects people's physical and mental health and all areas of their lives, often putting a strain on their relationships with loved ones and friends.

Justifying, explaining and trying to get symptoms recognised and validated is a big part of people's experience. In seeking treatment or support, people spoke about problems accessing appropriate healthcare, being misunderstood by family or friends, and feeling under pressure from employers to say when they would be well enough to return to work. Almost half of the people who completed the survey said they felt they contracted COVID-19 during the first wave before community testing was available. For some, this seems to increase their difficulties accessing services or receiving support through employers because they can't prove they ever had COVID.

#### *A patients experience*

*"... the symptoms. I know about them alright. Like horses on a roundabout they'd come, go, then come back round again, usually just at the point when you thought they'd gone: fatigue; exhaustion, crushing and endless; pain, everywhere - sharp, random, still, moving; breathlessness, breathing just stopping, chest pain, front and back; pins and needles, numb hands and feet; extreme nausea, throwing up, reflux, bloating, constipation, diarrhea, fluctuating temperatures, the freezing 'colds', when it feels like ice cubes are flowing through your veins; raging tinnitus, distorted smells and tastes; insomnia that lasts for weeks and weeks on end, disturbingly vivid dreams; twitching hands, limbs, tremors inside and out; my heart fluttering, palpitating; shocking headaches, from neck to eyes; hair loss both sudden; extreme, then insidious and never ending; dizziness, light-headedness, balance problems, disappearing spatial awareness, clumsiness, easy bruising, rashes, itchy skin, swollen veins, pain on even a light touch, crumbling fingernails, spilt fingertips; constant cystitis and cold sores, blurred vision, visual disturbances, sensory over-sensitivity (I never knew that sounds could HURT); and the cognitive problems: Diminishing memory, recall, acquired dyslexia it would seem; I transpose when reading aloud, when writing... and the words change order from the page to my mouth; forgetting what you're saying halfway through; forgetting why you got up, where you were going, how to drive, how to breathe and even speak- I stutter now; breaking things, constantly, and not having the energy to clean, sweep, or wipe them up. But most of all, the overwhelming, debilitating and soul-destroying exhaustion. It robs you of who you were. Who even am I now?"*

## How people experienced the symptoms of long COVID

Each person experiences long COVID symptoms differently. Often there is commonality but also differences. As an illness we now know can affect multiple organs and systems within the body, these variations are expected. Commonly symptoms are known to affect respiratory, cardiovascular, neurological, gastrointestinal, and musculoskeletal systems. However, this is not an exhaustive list.

*“Lots of symptoms have gone, others remain”*

Some symptoms are widespread in the first few months of long COVID. In our study, we found 26 symptoms experienced by more than half of all people responding. Eleven of these symptoms were shared by at least 75% of people, with the top five symptoms being almost universal.

Symptoms experience by more than 75% of respondents	
208	Shortness of breath
207	Brain fog and memory impairment
201	Extreme tiredness and fatigue
200	Feeling tired after cognitive exertion
192	Muscle aches
190	Post-exertional malaise
185	Difficulty sleeping
183	Chest pains or tightness
182	Irregular heartbeat
180	Joint pains
173	Anxiety

Other common symptoms in the earlier stages of long COVID included tachycardia; depression and low mood, coughs, pins and needles; unexplained sweating or chills; sore throats; altered sense of smell or taste; feeling dizzy or faint; lower back or kidney pains; nausea, weight gain, changes to vision and abdominal pains. 50-75% of people completing the survey reported each of these symptoms.

Other symptoms, including speech and language impairments, skin conditions, hair loss, urinary problems, confusion, tinnitus, persistent fever, and weight loss, were experienced by at least 1 in 4 people.

## Changes and Fluctuations over time

We know that characteristic of long COVID is a pattern of ‘fluctuating’ or ‘relapsing and episodic’ symptoms. Fluctuations can often occur within a few hours or over weeks and months. Other research found that people living with Long COVID sometimes characterise their experiences as unpredictable in nature<sup>5</sup>.

However, we also found that the five most reported symptoms were also reported to be the most persistent symptoms: tiredness and fatigue; brain fog and memory impairment; tiredness after cognitive exertion; post-exertional malaise and breathlessness. These constant and ongoing symptoms cause problems for 3 out of 4 people living with long COVID.

Persistent symptoms. Experience by more than 75% of respondents	
201	Extreme tiredness and fatigue
188	Brain fog/memory impairment
183	Tired after cognitive exertion
180	Post-exertional malaise
167	Shortness of Breath

This does not mean that other symptoms became any less significant over time, and many symptoms continued to be experienced by more than half of all people. Including physical symptoms such as muscle aches, joint pains, headaches and migraines; chest pains or tachycardia continue to be reported by more than half of people.

*“I’m concerned about my brain function, I still forget people’s names, leave pots on hob, etc.”*

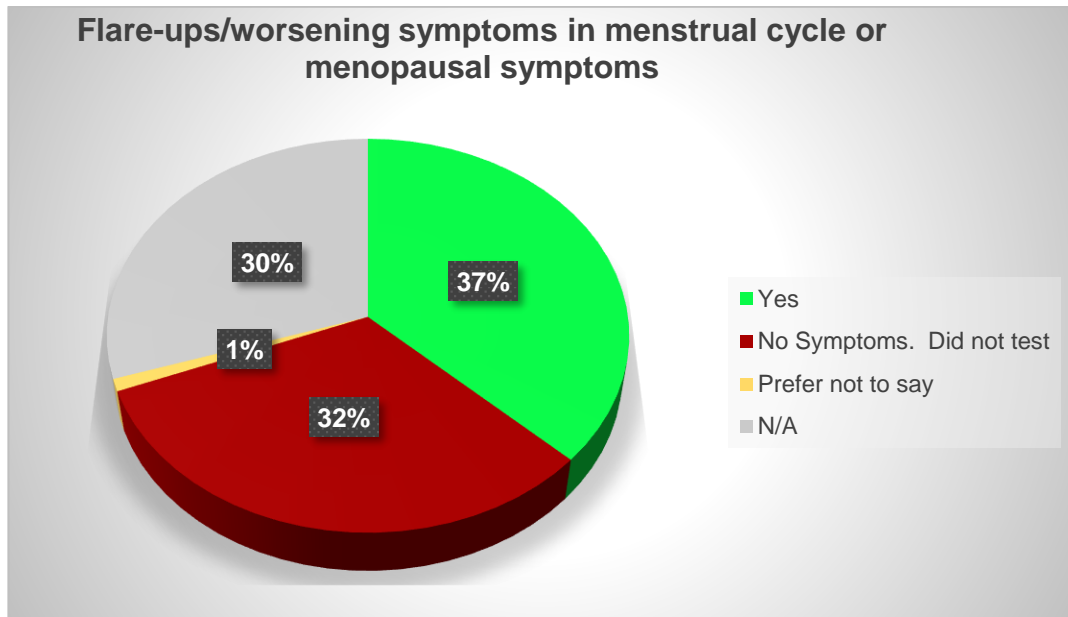
There is a significant impact on mental health and well-being, with more than half of people saying that they have developed ongoing symptoms of anxiety and depression. This may result from living with persistent physical symptoms for so long.

Persistent symptoms. Experience by 50-75% of respondents			
164	Muscle Aches	134	Irregular heartbeat
154	Joint Pains	132	Chest Pains or tightness
149	Headaches or migraines	119	Tachycardia
143	Difficulty Sleeping	112	Depression and low mood
139	Anxiety	113	Abdominal pain
136	Feeling faint or dizzy		

<sup>5</sup> Brown DA, O’Brien KK Conceptualising Long COVID as an episodic health condition *BMJ Global Health* 2021;**6**:e007004

## Long COVID and reproductive health

Long COVID seems to be more prevalent amongst women than men. Discussions in long COVID communities, online chat groups, social media and support groups showed that as well as experiencing common symptoms of long COVID, women felt that their illness was affecting their menstrual cycles or menopausal symptoms. The voice of lived experience is consistently backed up via research surveys, which also reflect similar findings that women between the ages of 30-49 are more susceptible to long COVID than men.



In our survey, over 50% of women said they experienced flare-ups or worsening symptoms with their menstrual cycle or menopausal symptoms since developing long COVID. Symptoms included experiencing irregular periods, unusual clotting, worsened premenstrual syndrome (PMS) and an increase in the severity of their long COVID symptoms around the time of their period.

Some long COVID symptoms of fatigue, heart palpitations, sweating, and sleep disturbance are also associated with perimenopause and menopause. Not recognising that symptoms could be similar, or overlap could lead to diagnostic overshadowing or misdiagnosis leading to a missed opportunity to provide treatments.

For women, there is an urgent need to better understand the inter-relational relationship between long COVID and their reproductive health to develop treatment plans and to reduce further risks to women's health.

## Our experiences of accessing health and social care

Scotland has not invested in Long COVID Clinics. Instead, the treatment pathway advocated by the Scottish Government is through GP practices and Primary Care. The Scottish Government have said:

*“Our response to long COVID depends on having a range of well-integrated sources of support, given the wide spectrum of needs that people affected can sometimes have.*

*This range of support is already being delivered by our NHS, social care and third sector across Scotland. We have an approach in place that will strengthen the range of support available within the primary care setting, providing a person-centered response with referrals to secondary care where necessary”<sup>6</sup>.*

We found the reality for most people who responded to be very different. Months after becoming ill, people described deep frustrations with primary healthcare and access to secondary specialist services.

People described feeling ignored, disbelieved or not taken seriously by their GPs. This, in many cases, included doctors refusing to give a diagnosis of long COVID, particularly where the person had not tested positive for COVID-19, usually because testing was not available when they first developed symptoms.

Others have said that whilst GPs have been sympathetic, their knowledge of Long COVID and what secondary care services are available are limited.

*“I feel let down and forgotten”*

*“Most management techniques have been learnt from patient groups/ private consultants (where the NHS would not run tests or prescribe medication) or self-taught.”*

Long haulers struggling with complex symptoms including fatigue, pain, tachycardia, and 'brain fog' often said that they felt that symptoms were dismissed or minimised, being told "you have to expect that" with minimal investigation done despite the severe impact these long COVID symptoms are having on the person.

Where people reported having had tests and investigations, most were carried out in primary care settings. Commonly these included blood tests, urine samples and liver and renal function tests. Some reported having been sent for chest x-rays or ECGs, with the results going back to the GP. However, results came back as "normal", often with no follow-up to secondary care services.

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<sup>6</sup><https://www.gov.scot/publications/coronavirus-covid-19-scotlands-strategic-framework-update-november-2021/pages/10/>

Over the last year, research has found some tests that may be beneficial, such as micro-clot testing. In the UK, testing for micro-clots is not available on the NHS, and nobody in our survey reported having had a micro-clot test. There is no consistent diagnostic pathway for long COVID, and some health professionals are unaware of how to proceed with the appropriate investigation. Even if patients are referred for investigation, it does not mean they will be seen by a specialty or seen quickly; several people reported waiting months after a referral has been made.

## Access to Private healthcare

*“Forced to go private and taking out a loan, I am seeing a cardiologist very soon and tests (echocardiogram, MRI) will then follow “*

This frustration at the lack of access to testing and investigations has left long COVID patients, especially those from the first Covid wave, desperate to get help. We found 49 (22%) people saying they paid to access tests privately. In health terms, this is a high number of people accessing private health care as roughly only 11 per cent of the UK population has some form of private medical insurance. One woman desperate for treatment described having taken out a loan she could ill afford to access diagnostics.

*“I paid about £800 for an echocardiogram as a history of heart issues in my family (including a heart transplant and 5 heart attacks) left me terrified of dying and the NHS waiting list for cardiology, despite knowing this history,*

As well as through private healthcare, some people could access some treatments through local charities or by taking part in research trials. These were often seen to be beneficial but are not widely available.

*“I saw a big improvement in my energy levels when I started oxygen therapy at a local charity, in October 2021”*

## Access to Social Services

Long COVID symptoms can be seriously debilitating and cause problems with self-care and management at home. Still, people may benefit from having aids and adaptations at home. Several people told us they did not know they could ask for help from social work or were told that no support was available. As well as through private healthcare, some people could access some treatments through local charities or by taking part in research trials. These were often seen to be beneficial but are not widely available.

“I have tried to make referrals both have continually been told there is nothing available, or that someone will respond. This has been the case for 15 months now

The most common support offered was in aids and adaptations. This was predominantly through self-referral rather than GP referral. Some people did receive help through local social services departments.

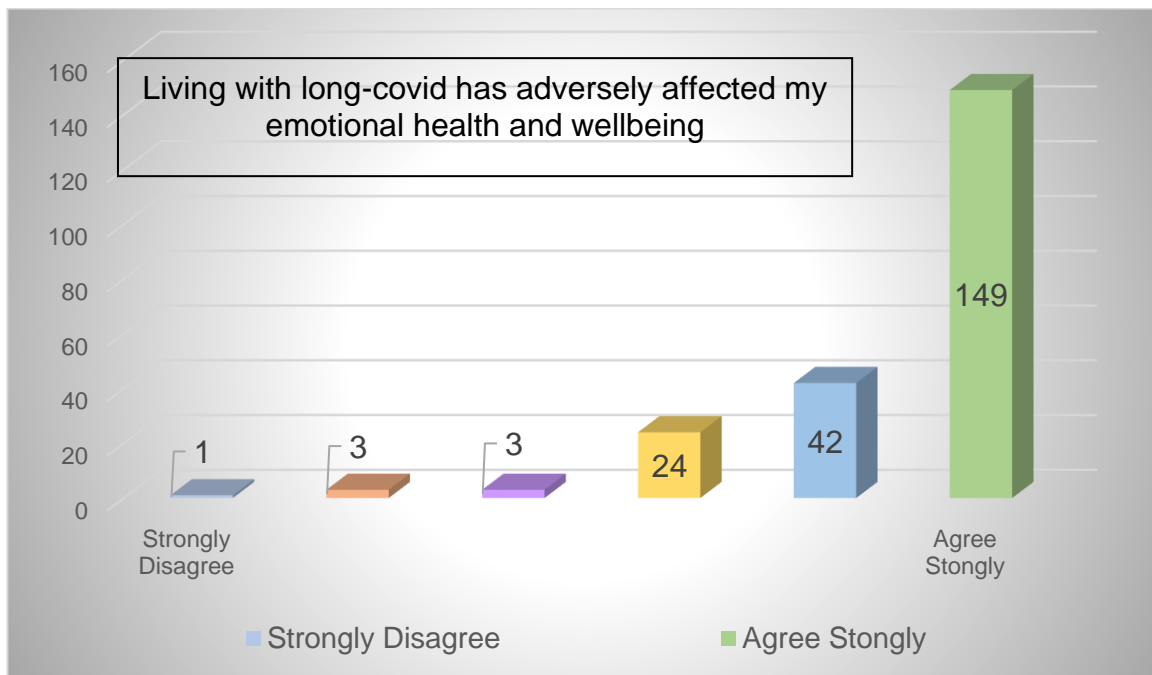
Most common were kitchen stools (5 people) and shower stools (6 people), but also bath seats (2) bath board (4) toilet seats (2) grab rails installed in the shower. One person had bed rails, and one had rails fitted at their front door to aid with steps.

Some people had help with their mobility, including walking sticks (4) and wheelchairs (4). Two people said they had received a disabled parking badge

Only one person mentioned any home care help provided, including daily support to shower and take out for a walk. Initially, one had carers four times a day. Another person had asked for an assessment for Self-Directed Support but received no response.

## The impact on our mental health and wellbeing

People reported a significant impact on their mental health and well-being because of long COVID. We know that long COVID can cause a prolonged inflammatory and immune response in the body. Such an inflammatory response, particularly in the brain or central nervous system, is also associated with feelings of anxiety and depression. However, this is not the only factor, and there are many reasons why people with long COVID report long COVID affecting their overall feelings of well-being.



More than half of the people said they have developed ongoing symptoms of anxiety and depression. Sometimes, this was described as a symptom or a response to other symptoms, i.e., loss of sleep or constant fatigue, which were seen to impact mood.

As a new illness, we do not know how long people will suffer from long COVID, when they will recover or even if they will recover. Prolonged and chronic illnesses are known to significantly affect a person's life, needing to adjust to changes and cope with added stressors.

Public attitudes towards long COVID have not helped. These can often be hostile and dismissive, with people facing negative comments or abuse in person or on social media.

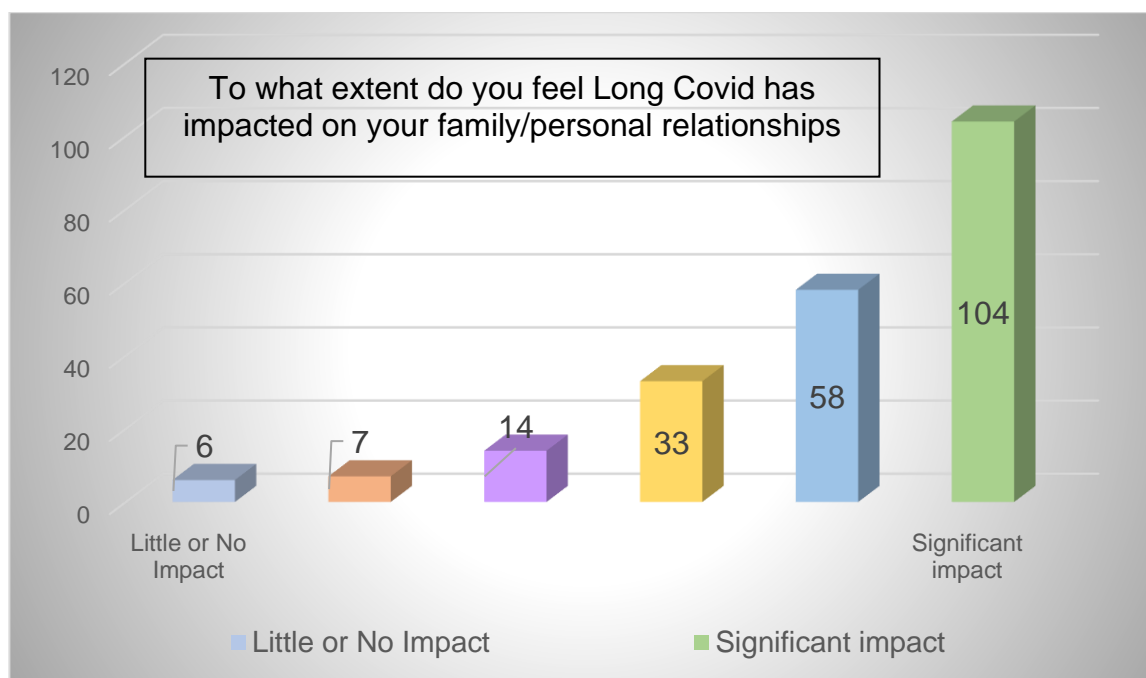
Negative or unsupportive comments from family and friends, health professionals, employers and co-workers wanting to know when you will be better lead to people feeling isolated, unsupported, and alone.

The feelings of social ostracism, rejection and devaluation are likely to affect emotional wellbeing negatively. As society talks about recovery from the pandemic, those impacted by long covid feel left behind in a society trying to return to life before the pandemic.



## The impact on home and family life

Long COVID, in common with other severe illnesses or disabilities, not only affects the individual but has an impact on the whole family. Long COVID can affect the entire family dynamic, increasing pressures and tensions in family relationships. As a disabling and limiting condition, people described how it can disrupt family activities and affect daily routines and caring responsibilities. In particular, the impact on young children who often find it difficult to conceptualise illness. One parent described their child as saying they “wanted their mummy back”.



Often the stress of these new pressures can increase the unmanageability of illness or lead to loss of self-esteem if the person feels that they have become a burden on partners or other family members.

*“I still can’t do many household tasks. Still can’t walk kids to school”*

Without significant support, people with long COVID are likely to feel excluded, rejected and left behind. Not only will exclusion lead to lower employment, impact children’s education, and make individuals and their families vulnerable to poverty, but it is likely to have an economic impact across communities and society.

## Children and Long COVID:

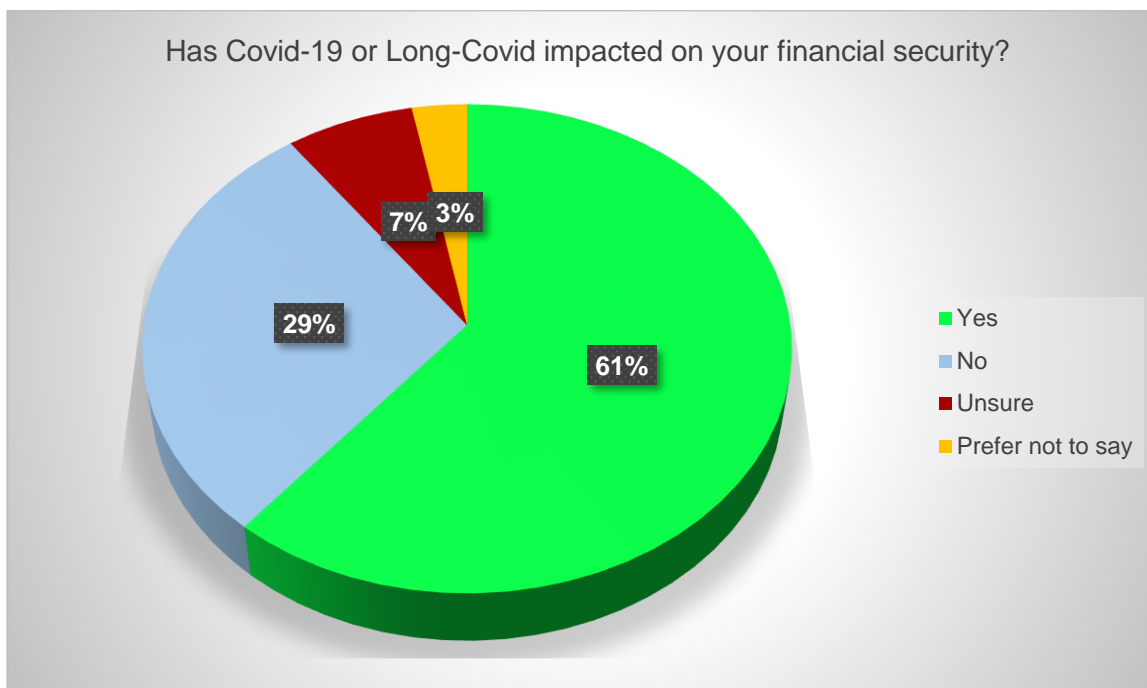
The public health message remains that children are mainly unaffected by Covid, even though the virus has effectively disabled many children. The long-term consequences of Covid are still unclear, but the lived experience of parents and young people with long COVID is a testament to the damage that Covid continues to cause.

Long Covid Scotland often hears the voices of parents describing the devastating impact of long COVID on their children. We are proud of our association with Long Covid Kids in Scotland and their work to highlight the devastating impact that long COVID can have on childhood.

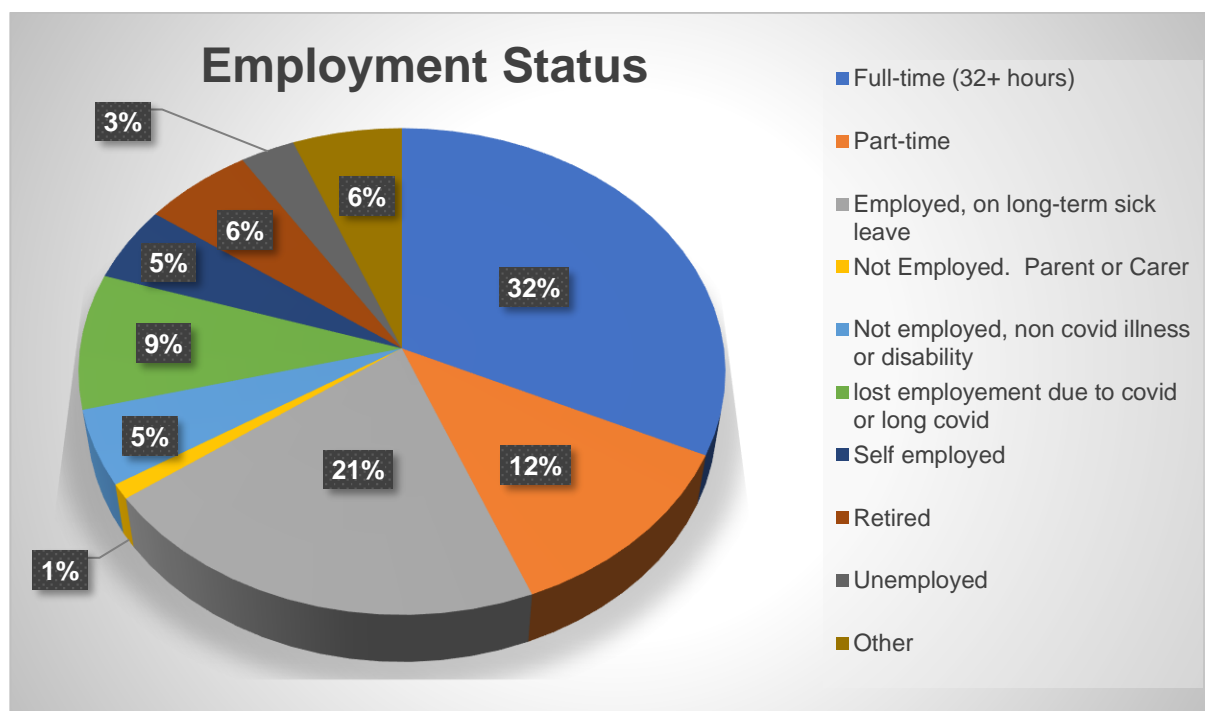
“The lives of my family have been turned upside down due to my 15-year-old son having Long Covid. With no clear diagnosis or treatment plans, we are very much left unsupported and unsure of what the future brings.”

## Financial Insecurity

61% of people reported that they faced added pressures on their financial security since contracting long COVID. Often this was linked to anxiety and depression, mounting debt worries over bills, familial or relationship pressures and employment concerns.



Employment was a big concern. Around 70% of people had full-time employment at the start of the pandemic, and another 12% were part-time. However, long COVID is having a substantial impact on employment.



People spoke about a reduction in income for themselves or for another family member, reductions in working hours, concerns over long-term sick leave, and loss of earning from self-employment because their ability to work had been significantly reduced, affecting their earnings.

Long COVID Scotland is so concerned about the employment consequences of long COVID that we launched a separate questionnaire in March 2022 to explore the impact further.

### Social Security

Access to benefits was also highlighted as a concern for people. In our survey, 20 people had lost their employment since becoming unwell. 14 people had claimed Employment Support Allowance, but only nine were successful. One person successfully appealed, and another said the benefit started but was unexplainably stopped.

47 people said they had made a claim for Personal Independence Payments, but most of these applications were still being assessed at the time of survey completion. We know that people can be waiting 6-9 months for a decision, and if not awarded benefits, they must decide whether to face a lengthy and stressful appeals process.

Of the people who applied for benefits through the DWP, 70% said they were dissatisfied with the service they received. Reasons were often due to the lack of information, the time to process claims or the poor quality of medical assessments.

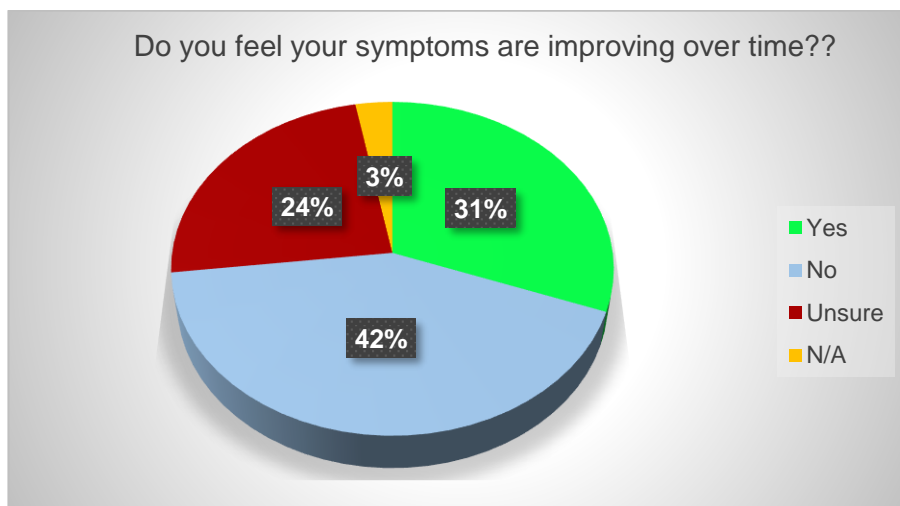
## Understanding our recovery journey

Recovering from long COVID can be a lengthy process. Just like symptoms can vary, the length of time it will take for people to recover will vary from person to person. We hope that everyone will get better and get better quickly. However, it is taking a long time for many of us, and some people now question and even doubt if they will ever recover.

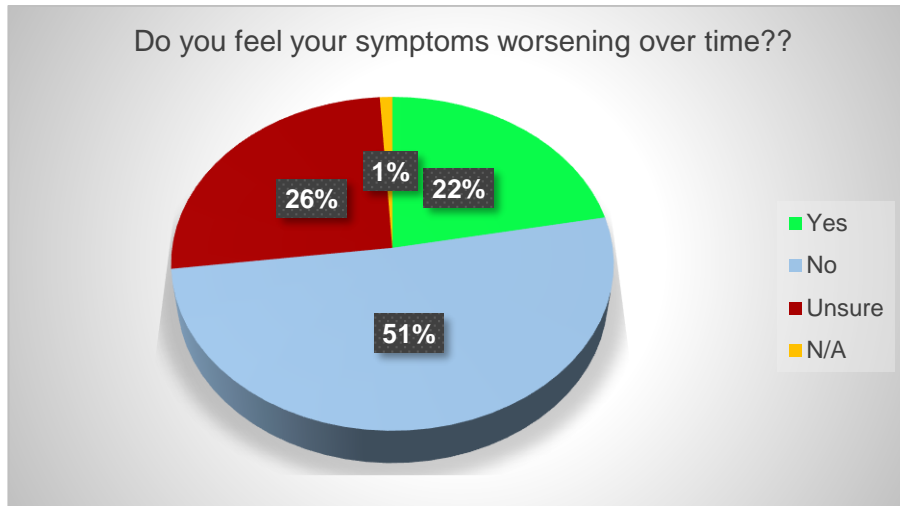
Our experiences of recovery are mixed. Progress in recovery was described as slow, gradual and incomplete, with experiences of relapse common.

*“It’s been very, very slow progress and I have to adapt my life around this breathing”*

When asked about improvements in their long COVID symptoms, only 31% of people reported feeling gradually better over time, and 43% of people felt that there was no real change.



When asked about any deterioration in their long COVID Symptoms 21.8% of people reported gradually feeling worse over time.



Relapses were extremely common. 83.8% of people said that they experienced relapses with symptoms flaring, making it challenging to define their recovery pathway. Often people link relapses to stress, exercise, keeping employment or study, and, occasionally, dietary causes.

*"I can work, or I can practice self-care. I can't really do both. I can't exercise or do the things that bring me great joy. Work takes all of my energy reserves"*

Most people reported that they felt their health was significantly poorer than pre- covid levels. People often say that symptoms can be cyclical, with new symptoms appearing months into the long COVID diagnosis and others, sometimes temporarily, disappearing. This can make it difficult for people to put a measure on their recovery.

*"Worsened in big steps due to big stressors - trying to stay in work, trying to get help from doctors, losing my job, getting the vaccines, applying for benefits, finally getting some help but so debilitated that getting help is too much exertion for me so not even capable of getting the help now ("you're too ill for this service" - me/cfs clinic)"*

Many people highlighted the impact of long COVID on their quality of life. A common theme was the trade-offs needed, for example, only being well enough to work and not doing any leisure activities afterwards. Many people reported needing at least 12 hours of rest a day because of tiredness and fatigue.

Progress in recovery, where it does happen, was widely reported to be slow and still incomplete with only one person reporting that they had made a full recovery and that their health had returned to what it was pre-covid.

*“I know I'm lucky that I have just enough energy to be able to work (office work) but it's more that I don't have any other choice financially anyway. It also means going to bed straight after most of the days whereas I used to have a very active and full after work life like rugby practice or spinning class and university evening classes. Walking is the only exercise I do, and I sweat profusely while doing it, even slowly”*

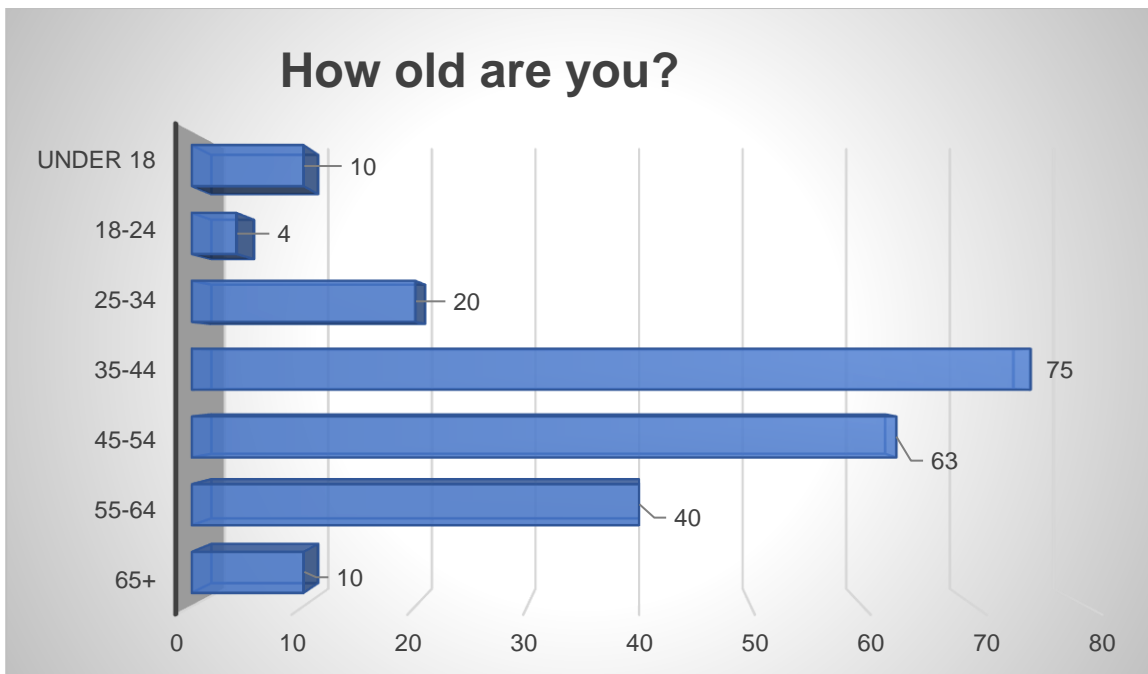
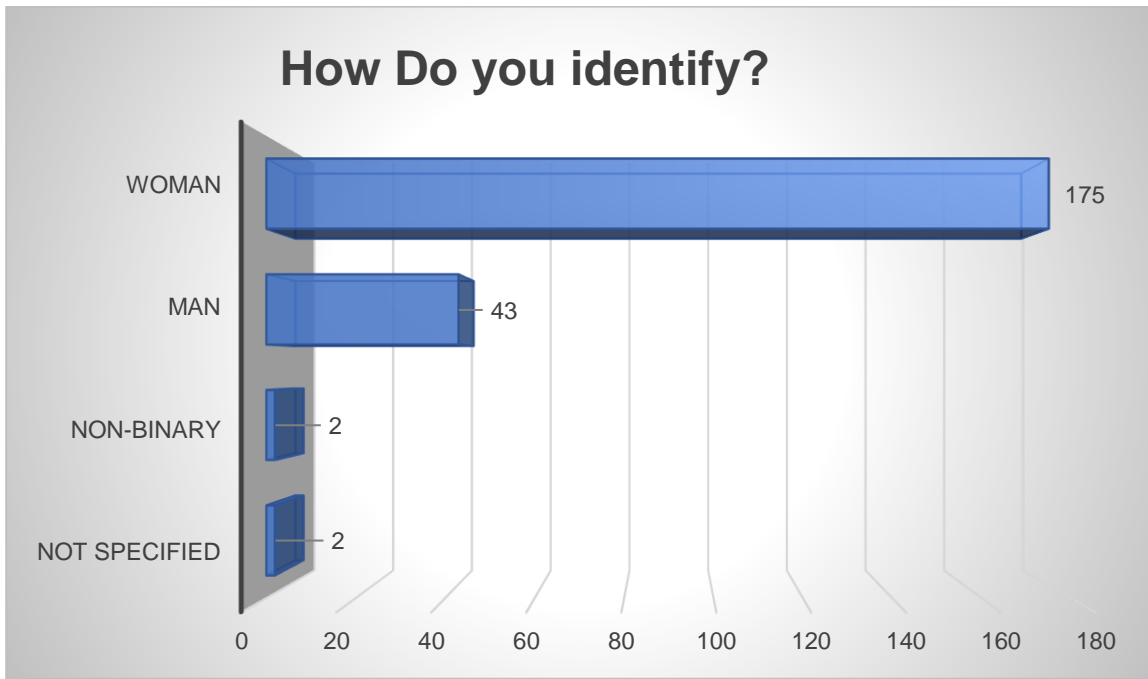
People spoke about a lack of help and understanding about what recovery could or should look like. Again, the lack of tailored support left people feeling let down and forgotten by the health care system. Numerous responses mentioned the belief that support in Scotland is lagging behind that in other countries.

*“I feel let down and forgotten. The lack of connected treatment and long COVID specialism in Scotland is a huge let down compared to other countries.”*

## Recommendations

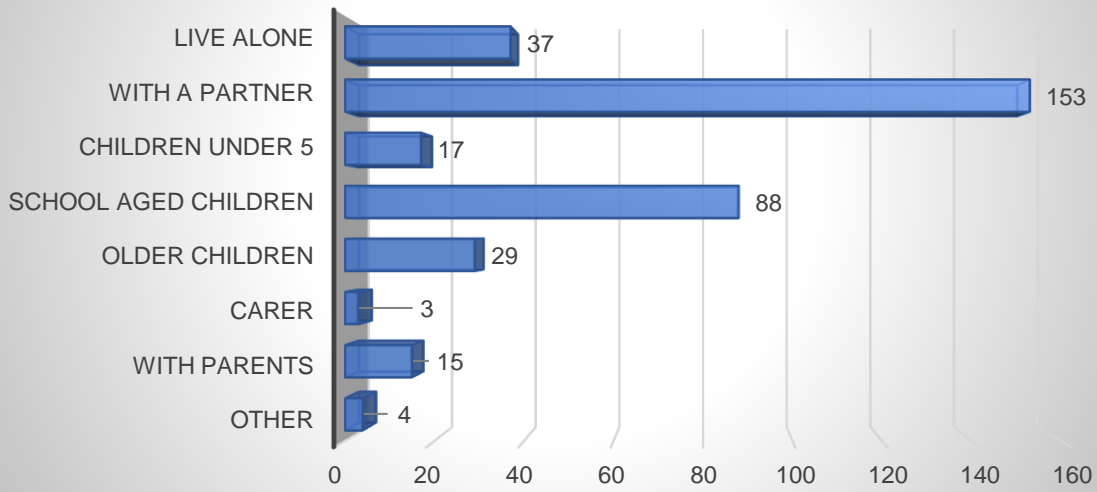
- The Scottish Government, Local Authorities and NHS Boards must put in place and publish robust plans ensuring fair access to health & social care, education & employment for people affected by long COVID
- All public bodies have a statutory responsibility to involve people in developing and delivering support and services. We expect these to be co-produced with people living with long COVID in a clear, transparent and demonstrable way.
- We need investment in public health messaging, raising awareness of long COVID, and eliminating the stigma faced by people living with long COVID.
- We need patient-informed services across Scotland including long COVID-specific clinics and services with clear pathways for treatment and support, including pediatric long COVID services.
- We call on the Scottish Government to invest in mental health support for people with long COVID. Including access to trauma-informed counselling services focusing on patient-informed psychological support.
- Health professionals need to receive ongoing relevant long COVID training. We welcome guidance from NICE, RCGP and SIGN, however, patients too often report that health professionals lack understanding or information on long COVID.
- To inform future policy, we ask the Scottish Government to establish a long-COVID register to track and monitor long COVID in Scotland. Including prevalence rates, symptoms, prescribed treatments as well as rates of recovery and disablement.
- Additional funding is needed to fund active pilots and trials of new treatments such as micro-clot testing or hyperbaric chamber treatments putting into practice national and international learning.
- We call on the Scottish Government and the Chief Scientists Office to make it a requirement of any long COVID research award to be inclusive, co-produced, and involve people with long COVID as equal partners at every level.
- The long COVID community has been the leader in supporting people living with long COVID and leading the way in patient advocacy. This includes providing compassionate support and responding to trauma, loneliness and isolation. We are tired of being left out of the funding tree and call upon the Scottish Government to provide proper funding directly to long COVID communities to continue the valuable contribution they are making.

Appendix  
Demographics

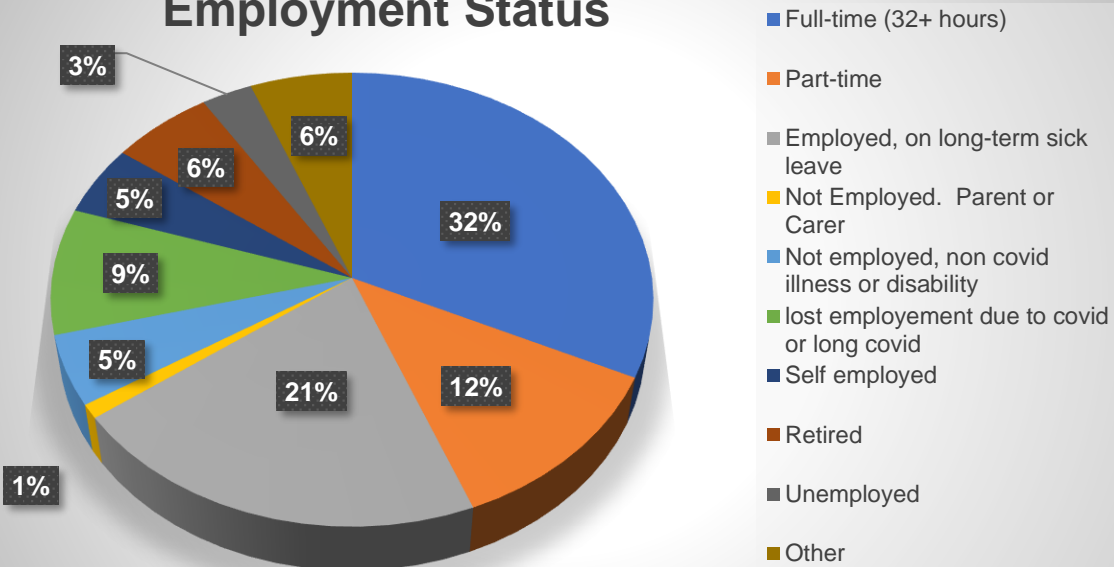




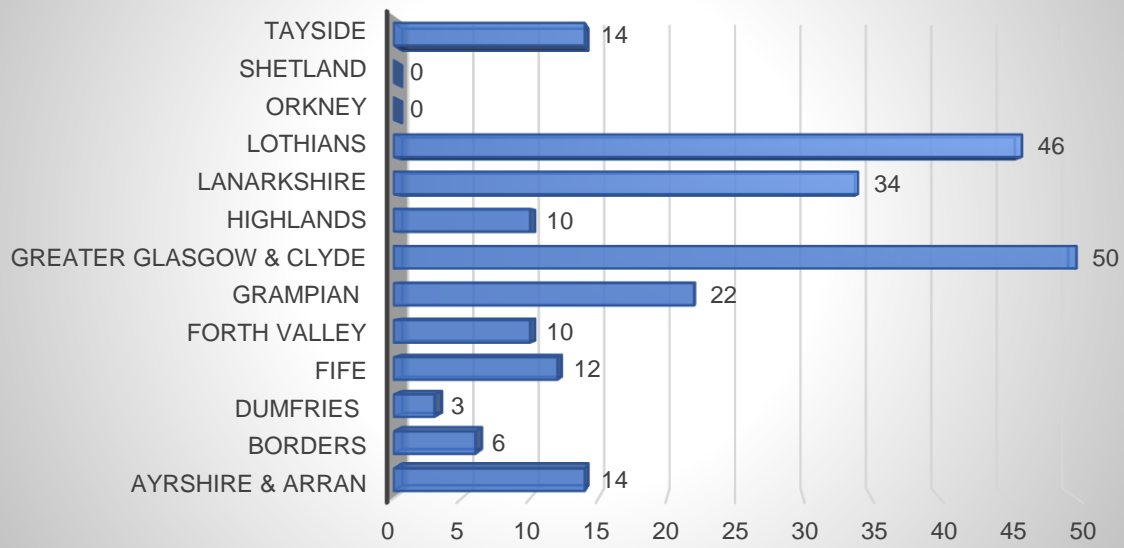
## Who else lives with you as part of your household.



## Employment Status



## Health Board Area





# LONG COVID SCOTLAND

2022



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