

Workers' experiences of long Covid

A TUC report

Acknowledgements

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Summary

In every sphere of life across the UK for over a year the impacts of Covid-19 have been massive. However, as we edge nearer the date where the final level of government restrictions will be lifted there are indications that Covid-19 could have a far longer effect. As well as the economic impact of the pandemic which will be felt for years to come, evidence is showing that long Covid is affecting increasing numbers of people. The Office for National Statistics (ONS) has found that in May 2021 around one million people in the UK were affected by Covid-19 symptoms that lasted longer than four weeks. Nearly two-thirds of these people reported experiencing a negative impact on their day-to-day activities. People of working age are among the groups most likely to be affected.

There has rightfully been increasing attention on long Covid and the impact that it is having on people's lives but very little of this discussion to date has focused on the workplace. We, therefore, conducted an online survey to better understand workers' experiences and make evidence-based recommendations. Over 3,500 people who had had Covid-19 responded: around 3,300 of whom self-reported having long Covid. The majority of these were key workers (79 per cent); people who faced higher levels of exposure to Covid-19 while keeping the country running during the pandemic.

Almost three in 10 respondents (29 per cent) had been experiencing long Covid symptoms for 12 months or more. This length of time is significant because in order to be protected under the disability provisions of the Equality Act 2010, a person has to have a condition that has a substantial and long-term impact on their ability to do normal day-to-day activities. Long term is usually taken to mean 12 months or more. Disabled people are protected by the Equality Act from discrimination, harassment and victimisation. Employers also have a duty to take steps to make sure that disabled people can access jobs as easily as non-disabled people: known as the duty to make reasonable adjustments. Reasonable adjustments can include flexible working arrangements, longer rest breaks, specialist software or equipment. It is clear from our findings that workers with long Covid urgently need this protection, whether they have had symptoms for 12 months or not.

Workers reported experiencing a range of symptoms. On average each respondent reported having nine of the 21 long Covid symptoms we asked about and described the severity of their cumulative impact. Nine out of ten respondents experienced fatigue, with other common symptoms centred around problems with brain fog (72 per cent), shortness of breath (70 per cent), difficulty concentrating (62 per cent) and memory problems (54 per cent). Over four in five respondents (83 per cent) reported experiencing at least one of a range of pain-related symptoms with around one third (32 per cent) experiencing depression.

Respondents also described the poor treatment that they experienced at work because they had long Covid. Over half (52 per cent) had experienced some form of discrimination or disadvantage. Workers were faced with disbelief and suspicion, with around one fifth (19 per cent) having their employer question the impact of their symptoms and one in eight (13

per cent) facing questions from their employer about whether they had long Covid at all. Respondents were also concerned about what the future might hold for them at work given the amount of sick leave they had been forced to take due to their long Covid symptoms. For around one in six respondents (18 per cent), the amount of sick leave they had taken had triggered absence management or HR processes and one in 11 respondents (9 per cent) had used up all of their sick leave and had been told there would be negative consequences if they took more. One in 20 respondents (5 per cent) had been forced out of their jobs because they had long Covid.

Trade unions have worked throughout the pandemic to keep workplaces safe and protect workers. We have challenged employers and the government over inadequate sick pay that makes it difficult for low paid workers to self-isolate, failures to provide adequate personal protective equipment (PPE) and testing, and the urgent need for investment in safety regulation and enforcement.

Unions have played a major part in keeping workers who have contracted Covid-19 at home and not in the workplace and protecting those at higher risk. Thousands of [union health and safety reps have spent more hours each week](#) carrying out their role compared to previous years, some doing so in their own time. Unions have also worked to recruit and train more safety reps, with approximately 110,000 now in workplaces across Britain.

It is clear from our findings that too many workers have been and continue to be failed by their employers. Several workers described contracting Covid-19 at work, with some expressing the anger they felt at the inadequate provision of personal protective equipment (PPE) and lack of attention to other safety measures which they felt had led to transmission. The fact that they now face negative treatment from the same employers because of their long Covid symptoms, adds another layer of injustice to their experience.

A public inquiry is urgently needed to ensure that we never repeat the failures that shaped the experience of frontline workers during the pandemic. This must include examination of the experiences of workers with long Covid. A recommendation by the Industrial Injuries Advisory Council on Covid-19 prescription is also expected: this recognition could provide workers with financial support and assistance in pursuing claims.

Covid-19 has exposed huge inequalities in the world of work. However, if we do not take steps now to ensure that workers with long Covid are properly protected, we run the very real risk of new, long lasting inequalities being created.

Recommendations

Government

In all responses to long Covid, government should ensure that they engage throughout with disabled workers, in particular those with long Covid and their trade unions and ensure that the voices and experiences of disabled people are at the heart of all planned activity.

Government should:

- 1. ensure that disproportionate impact of Covid-19 on different groups of workers - including those with long Covid symptoms - is included within an independent public inquiry**

Alongside scrutinising the quality of decision-making across the pandemic response in government, the public inquiry must look at some of the unequal and long-term impacts on different groups of workers, including Black and Minority Ethnic workers and those in insecure occupations among whom Covid-19 mortality rates are disproportionately higher. This should include an examination of the impact of long Covid - which this report shows has impacted on large numbers of key workers - and the kind of support those workers have received as a result.

The inquiry must also examine the impact of the failure to provide frontline workers with adequate personal protective equipment (PPE).

We believe the voices of workers and the families of those who contracted the virus at work must be heard through the public inquiry into the government's handling of the Covid-19 pandemic that the Prime Minister announced in May. This will be central to understanding what went wrong and learning lessons for the future.

- 2. strengthen the Equality Act 2010 by specifying that long Covid is a disability**

This could be achieved by using [secondary legislation](#).

The TUC believes that this should happen for the following reasons:

- This would be a way of society recognising the unprecedented risks and sacrifices made by many workers during the pandemic, and ensuring that we offer protection to those whose health has been seriously damaged. The Covid-19 pandemic is an unprecedented and tragic health crisis which has impacted us all. However, our research suggests that the burden of the pandemic has been shouldered unequally, reflecting existing fault lines of inequality across our society. In addition, many workers who now have long Covid are the key workers who were exposed to increased levels of risk during the pandemic as they continued to care for us and to protect, feed and deliver goods to us. We must now ensure that these workers do not suffer a double burden of discrimination and risk to their livelihoods.
- Long Covid is a condition which at times might not manifest itself in physical symptoms, but at other times may do. Even when there is no physical effect, there may still be the

potential for discrimination against workers with long Covid. For example, there may well be stigma attached to the condition. An employer who is made aware that a worker has long Covid may make an assumption that that worker cannot take on a promotion or cannot continue to work. In this way, we are of the view that long Covid is akin to other conditions deemed to be a disability.

3. adopt the social model of disability

One way of bringing the social model of disability into the heart of UK law would be to make the United Nations Convention on the Rights of Disabled Persons (UNCRPD) enforceable within UK law.

Fully incorporating the Convention would bring the added benefit of addressing one of the outstanding recommendations the UNCRPD to the UK on how to improve and make further progress against the Convention's aims.

4. provide access to Disablement Benefit

The Industrial Injuries Advisory Council (IIAC) is considering prescription of Covid-19 as an occupational disease in certain sectors. An industrial disease is an illness or a condition that can arise or be caused as the result of unsafe working conditions or exposure to certain substances in the workplace. If a decision, based on relevant data, is made to prescribe the illness in certain occupations, long Covid patients should be made eligible to apply for Industrial Injuries Disablement Benefit (IIDB).

5. increase and expand statutory sick pay

The weekly SSP rate must be permanently raised to at least the equivalent of a week's real living wage (£330 per week) and the lower earnings limit must be scrapped. This would guarantee that everyone who has to take time off work when sick would still at least be paid enough to live on.

6. overhaul Universal Credit so it is fit for purpose

We found that one in 20 respondents had been forced out of their job due to long Covid. Others may not be able to continue working given the severity of their symptoms. For those who cannot work because of long Covid the benefits system fails to provide adequate support. It needs an emergency overhaul to make it fit for purpose in line with recommendations set out in our earlier report on [‘The impact of the pandemic on household finances.’](#)

7. strengthen flexible working rights

It is likely that many workers with long Covid are already covered by the disability provisions of the Equality Act 2010, which would mean that they could ask for flexible working as a reasonable adjustment rather than having to rely on other workplace rights. However, as highlighted in our [recent report on flexible working](#), unless government acts to strengthen rights and ensure that flexibility is the default approach in a workplace, there is a real risk of stigma and discrimination associated with flexible working patterns.

The government must introduce a legal duty on employers to consider which flexible working arrangements are available in a role and publish these in job advertisements, with

the new postholder having a day one right to take up the flexible working arrangements that have been advertised. If an employer does not think that any flexible working arrangements are possible, they should be required to set out the exceptional circumstances that justify this decision.

And they must introduce a day one right to request flexible working for all workers, with the criteria for rejection mirroring the exceptional circumstances set out above. Workers should have a right to appeal and no restrictions on the number of flexible working requests made

8. invest in regulators

HSE: The last ten years have seen real-term cuts of 50% to the HSE budget, with local authorities seeing their inspectorate numbers fall, too. This must be reversed to ensure safety regulators are well-equipped to investigate workplace health risks and take swift action against employers to prevent poor practice.

Covid-19 has further exposed the need for effective, quality enforcement that rewards best practises and punishes those who put workers at risk. This means a long-term investment in the HSE's inspectorate capacity and local authority environmental health teams to allow for fully-trained inspectors, infrastructure and resources needed to keep workers safe.

EHRC: The EHRC should receive additional ring-fenced resources to use the full range of their powers to address discrimination against workers with long Covid.

9. provide universal access to occupational health

Only half the UK population has access to occupational health (OH), despite its known benefits. Occupational health support could play a pivotal role in supporting workers with long Covid back into the workplace. There should be investment in expert OH advice in government, tax incentives so employers can invest in occupational health, and access to OH for GPs.

The Equality and Human Rights Commission

The Equality and Human Rights Commission should:

10. produce guidance for employers

Ahead of legislative change specifying long Covid as a disability for the purposes of the Equality Act 2010, EHRC should produce guidance for employers. This should be drawn up in conjunction with people with long Covid and set out the steps that employers can take to ensure workers can retain their jobs and return to work in a way that promotes their wellbeing. This guidance should highlight the different steps an employer can take to remove barriers preventing those with long Covid symptoms, including energy limiting impairments, from getting a job and thriving at work.

11. make targeted use of its enforcement powers

Carry out a programme of targeted work with their full range of enforcement powers to work towards eliminating discrimination against workers who have long Covid.

Employers

Employers should not wait for the government to specify that long Covid should automatically be considered as a disability for the purposes of the Equality Act 2010. They should act as if all staff with long Covid already have the full range of protections afforded by the Act, including putting in place reasonable adjustments.

Employers should also take the following actions.

12. review existing policies

Workplace policies should be reviewed in light of this report, in consultation with the relevant unions, workers who have long Covid and disabled workers to ensure that the policies appropriately address the needs of workers who have long Covid and take them seriously.

Employers should, in particular, look at their policies and practice in relation to phased return to work and energy impairments, taking into account the fluctuating nature of long Covid. Policies should reflect the fact that some workers might take a long time to recover from long Covid while others might never recover fully or return to their previous ways of working.

13. consult with trade unions and staff that have long Covid on steps to promote equality and eliminate discrimination

Employers should consult with trade unions and their staff who have long Covid on the best way to remove the workplace barriers that workers with long Covid face, recognising that they, and the trade unions that represent them, should be able to determine the solutions to the issues they face.

14. put in place reasonable adjustments for workers who have long Covid

Employers should ensure all reasonable adjustments are implemented in a timely manner.

15. record long Covid related leave separately from sick leave

Employers should record sick leave taken by workers who have Long Covid that is connected to long Covid separately from sick leave that is unconnected to this; in line with TUC's guidance on [recording sick leave taken by disabled workers](#), this would recognise that some workers who have long Covid may have different and higher forms of sickness absence.

16. review existing flexible work policies

In consultation with recognised trade unions, employers should review existing policies and make flexible working the default.

17. ensure workers with long Covid have return-to-work risk assessments

Where it is appropriate for workers with long Covid to return to workplaces, their condition should be factored into risk assessment and management, ideally conducting an individualised risk assessment. Certain activities may need adjustment on account of symptoms, to avoid risk of injury to the worker or others. For example, some safety-critical functions may not be appropriate for an individual suffering fatigue or so-called 'brain fog'.

Trade Unions

Unions should:

18. work with employers to review their policies and practices to ensure any barriers workers with long Covid face at work are identified and removed.
19. negotiate with employers for long Covid to be automatically treated as a disability so that employers put in place reasonable adjustments to remove workplace barriers and record absence linked to long Covid separately from other sick leave.
20. use the findings in this report to campaign to increase their reps' and members' understanding of long Covid so workers are better able to seek help if they need it.

Introduction

What is long Covid?

There is a growing body of evidence that Covid-19 can cause symptoms that last weeks or months after the initial infection has gone.

While many people who have Covid-19 will fully recover in a few days or weeks some people will have symptoms for longer. This is sometimes called post-Covid-19 syndrome or 'long Covid.' Throughout this report we refer to long lasting symptoms of Covid-19 as long Covid.

There is evidence that a growing number of people have Long Covid. Recently the Office of National Statistics (ONS) estimated that [one million people](#) living in the UK were self-reporting long Covid.

The [World Health Organisation](#) has stated that around one in 10 Covid-19 patients will still have symptoms 12 weeks later.

There is no agreed list of what symptoms make up long Covid. However, most studies agree it covers a broad range of similar symptoms. Our survey asked about 21 of the most common symptoms including energy impairments (aka 'fatigue'), difficulty concentrating (aka 'brain fog'), muscle pain, shortness of breath and joint pain.

Which groups are more likely to have long Covid?

Anyone can be affected by long Covid but [ONS data](#) shows that there are some groups that are more likely to have it. These are:

- people aged 35-69 years
- women
- those living in the most deprived areas
- disabled people or those with an existing health condition.
- those working in health or social care

However an ongoing issue, when analysing the disproportionate impact of Covid-19, is a lack of public understanding on what constitutes long Covid. This is likely to impact on people's ability to report it accurately. A further complicating issue is the fact that some workers who have symptoms of long Covid were unable to get a test to confirm they had contracted Covid-19 due to the difficulties that many experienced in accessing tests at the start of the pandemic.

Who is currently covered by the disability provisions of the Equality Act?

Disabled people are protected by the [Equality Act](#) 2010 from discrimination in employment and a range of other areas including education, provision of services and transport. All employers also have a legal duty under the Equality Act 2010 to proactively make reasonable adjustments to remove, reduce or prevent any disadvantages that disabled workers face.

The [Equality Act](#) defines disability as a “physical or mental impairment...[that] has a substantial and long-term adverse effect on [their] ability to carry out normal day-to-day activities”. Government [guidance](#) makes clear that 'substantial' means more than minor or trivial and 'long-term' means 12 months or more. The guidance also highlights the importance of considering the cumulative impact of multiple impairments that a person might have and states that even if individual impairments might not have a substantial impact if considered in isolation “account should be taken of whether the impairments together have a substantial effect overall on the person’s ability to carry out normal day-to-day activities”.

The guidance refers specifically to pain and fatigue related impairments, clarifying that although a person may have the ability to carry out a normal day-to-day activity they “may be restricted in the way that it is carried out because of experiencing pain in doing so. Or the impairment might make the activity more than usually fatiguing so that the person might not be able to repeat the task over a sustained period of time”.

There are certain specified conditions which mean that people are considered as disabled under the Act from the point of diagnosis. These are cancer, HIV infection or multiple sclerosis (MS).

Special provisions apply when determining whether the effects of an impairment that has fluctuating or recurring effects are long-term. If the substantial adverse effects are likely to recur, they are to be treated as if they were continuing. If the effects are likely to recur beyond 12 months after the first occurrence, government guidance states that they should be treated as long-term.

The disability provisions of the Equality Act also cover people who previously met the definition of a disability. People who continue to experience “debilitating effects as a result of treatment for a past disability” are also covered.

Currently, in order to be covered by the disability provision of the Equality Act 2010, workers with long Covid would have to take an Employment Tribunal and, on a case-by-case basis, prove their condition would have a substantial long-term adverse effect on the workers ability to carry out day-to-day activities. Taking an employment tribunal case is a significant burden for anyone, let alone workers who are experiencing long Covid symptoms.

Until there is more medical evidence on the likelihood of long Covid to last longer than 12 months, workers, who have had long Covid for fewer than 12 months, may not be covered by the Equality Act 2010 protections. During this time they could face discrimination and

job loss. Many workers who now have long Covid are the key workers who were exposed to increased levels of risk during the pandemic as they kept the country running.

Some disabilities, for example HIV, cancer and multiple sclerosis, are automatically covered by the Equality Act 2010¹ meaning workers benefit from the disability provisions within the Act from the point of diagnosis. We must ensure that workers with long Covid do not suffer a double burden of discrimination and risk to their livelihoods. Adding long Covid to the list of disabilities automatically protected by the Equality Act 2010 would help considerably with this.

Treatment of disabled people with energy impairments

In seeking solutions to the negative experiences of people with long Covid at work it is clearly vital to ground all solutions in the lived experiences and preferences of those who have this. However it is also important to reflect on the previous experiences of disabled workers with energy impairments like fatigue. Although Covid-19 and long Covid are new, it is estimated that around 250,000 people in the UK experience chronic fatigue syndrome (CFS) or myalgic encephalomyelitis (ME).

ME or CFS is a long-term, fluctuating, neurological condition that causes symptoms affecting many body systems, more commonly the nervous and immune systems.

People with ME/CFS experience debilitating pain, fatigue and a range of other symptoms associated with post-exertional malaise, the body and brain's inability to recover after expending even small amounts of energy. Not everyone will experience the same symptoms. Preliminary reports and data about long Covid symptoms and patient experiences contain many similarities to other chronic illnesses known to be associated with viral triggers, such as ME/CFS.

Workers with energy impairments have faced widespread discrimination and disbelief at work. Scepticism about the existence and extent of energy impairments like ME/CFS is widespread as highlighted in [a report by Chronic Illness Inclusion](#) which stated that "negative perceptions and misunderstandings around 'fatigue' and chronic illness create formidable yet unnecessary barriers to work. The widespread notion that fatigue is not a real disability stands firmly in the way of disability equality in work. Systemic disbelief of energy impairment affects disability disclosure and access to reasonable adjustments, and contributes to strained employment relations, sometimes causing unnecessary departure from the labour market."

The parallels between workers with energy limiting impairments and long Covid are clear. Going forward it is imperative employers understand energy impairments and learn the lessons from the previous experiences of people with ME/CFS, so that appropriate reasonable adjustments are put in place for workers who have long Covid, ME/CFS or other energy limiting impairments.

¹ These are covered in Schedule 1, Part 1 of the Equality Act 2010 and in Regulation 7 of the Equality Act 2010 (Disability) Regulations 2010.

Methodology

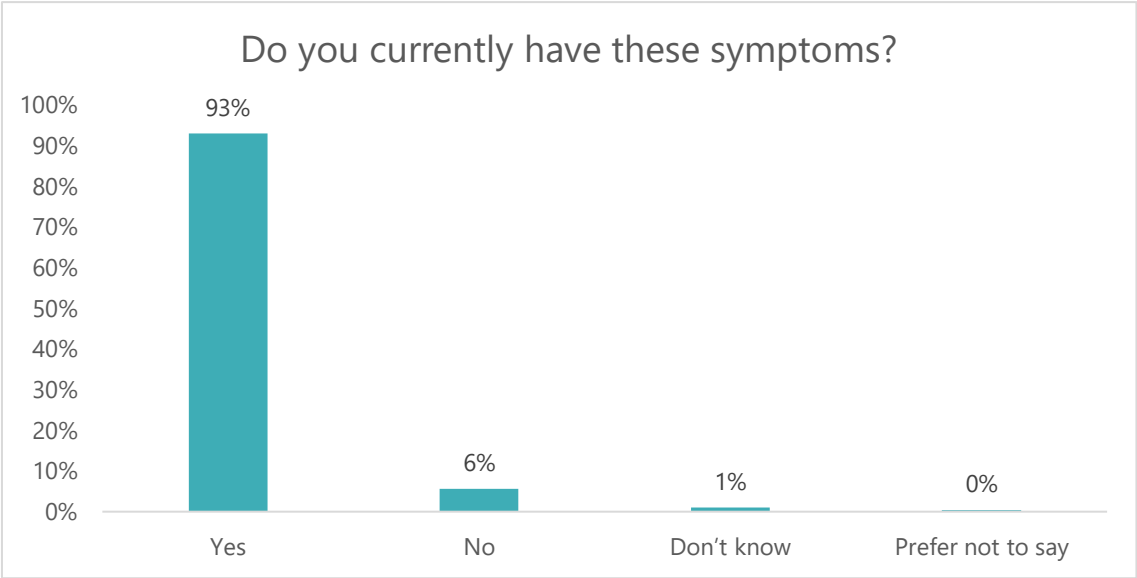
In order to better understand the experiences of workers who have, or have had, ongoing symptoms after having Covid-19, commonly known as 'long Covid', the TUC conducted research using a self-selecting online survey. The survey was open between 3 April and 27 May 2021 and was promoted on social media, through affiliated unions and long Covid support groups. We received 3,557 responses from people who self-reported that they had had Covid-19. Of these, 3,296 were from people who self-reported that they had long Covid.

Findings

Long Covid Symptoms

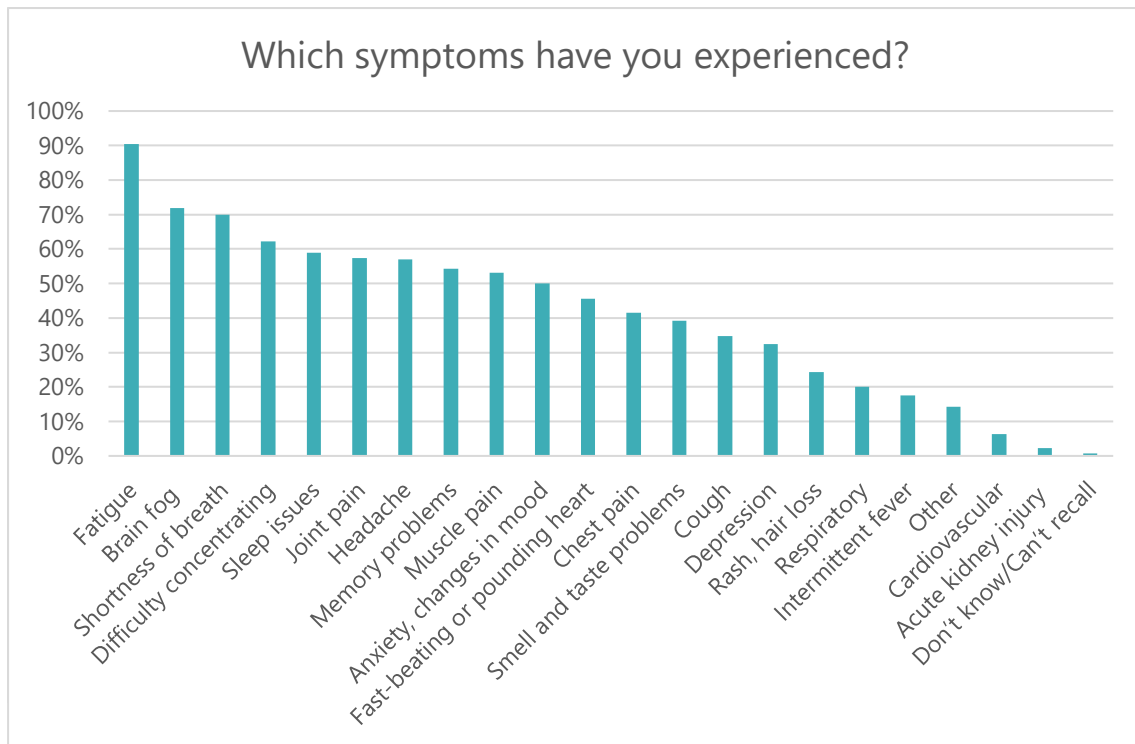
Current experience

Nearly all (93 per cent) of those who told us that they had long Covid were currently experiencing symptoms.



Length of symptoms

The most common length of time for respondents to have experienced symptoms was between 3 and 6 months (35 per cent). However almost 3 in 10 respondents (29 per cent) had been experiencing long Covid symptoms for 12 months or more.



Type of symptoms

The most common symptom was fatigue, which 9 out of 10 respondents said they experienced. Other common symptoms centred around problems with brain fog (72 per cent), shortness of breath (70 per cent), difficulty concentrating (62 per cent) and memory problems (54 per cent). Over half of respondents reported experiencing a range of pain-related symptoms; joint pain (57 per cent), headache (57 per cent) and muscle pain (53 per cent). Over two fifths (42 per cent) said they experienced chest pain. Half of respondents said they experienced anxiety or changes in mood with around one third (32 per cent) experiencing depression.

Around one in seven respondents reported other symptoms including vertigo, loss of hearing, tinnitus, loss of appetite, bladder weakness and blood clots. Respondents could select as many of the listed symptoms as was relevant to their experience of long Covid. On average each respondent reported having nine of the 21 long Covid symptoms we asked about and described the severity of their cumulative impact.

Respondents described the difficulties that they faced trying to work while experiencing a range of long Covid symptoms. One respondent who contracted Covid- 19 at work, when their employer went ahead with an international event in the first wave of the pandemic told us that:

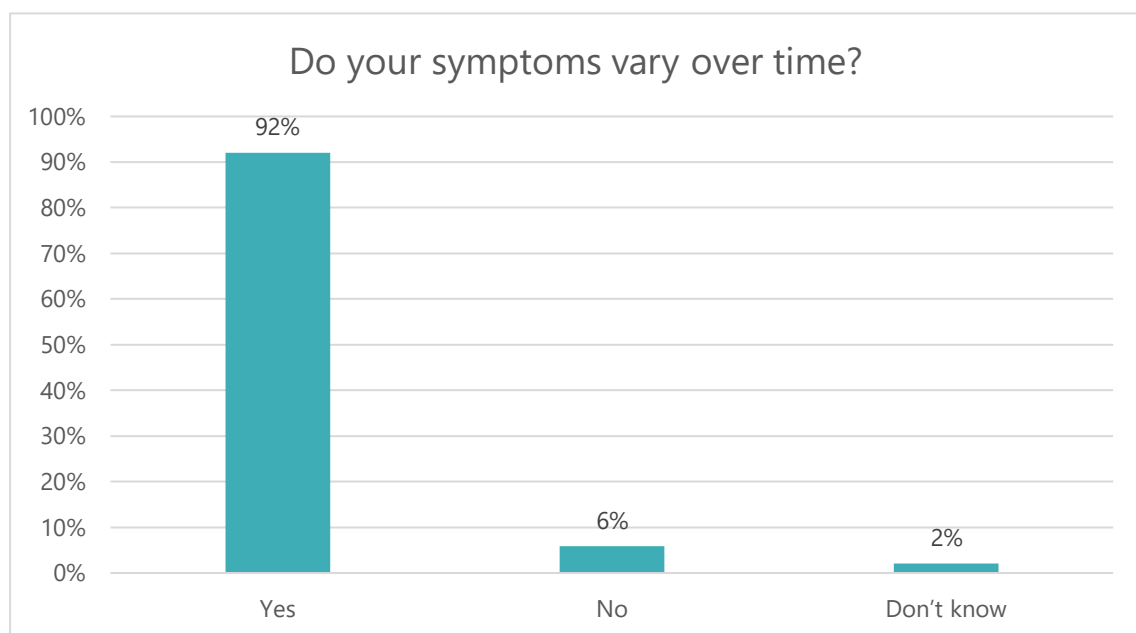
I was still expected to work long hours, handle stressful situations in impossible timeframes, find and fill in forms (which I struggled to do because of cognitive issues), spend hours on

zoom calls (when I struggled to talk and breathe, resulting in extreme chest pain , shortness of breath, exhaustion and severe symptom relapses)

Respondent working in IT, communications, media and publishing sector, 46-55, female, North West England

I travel by public transport 4 hours per day to and from work in addition to my 8 hours shift. It is extremely difficult to focus on my job due to extreme fatigue and joint pains at work

Respondent working in Public administration, defence and social security sector, 46-55, female, key worker, South East England



Fluctuating symptoms

The vast majority (92 per cent) of respondents told us that their long Covid symptoms varied over time, becoming worse on some days than others.

A number of respondents expressed frustration at the fact their employers and in particular their line managers didn't appear to understand their fluctuating symptoms and the impact of these, with some employers feeling that if symptoms were not experienced for a short period of time then this meant that the worker had recovered fully.

Until recently my line manager did not really grasp how much the symptoms fluctuate and that it made it difficult for me to book in too much face to face time with patients in case my brain fog was limiting my ability ... I had to spell it out for her - I cannot do back to back meetings, I cannot do meetings for over an hour etc, I would be exhausted

Respondent working in Health and social work sector, 56-65, female, key worker, Yorkshire and Humberside

I feel like my employers assume it's all settled down when in actual fact the symptoms have fluctuated

Respondent working in Health and social work sector, 36-45, female, key worker, Scotland

Current working situation of respondents

The majority of respondents (57 per cent) had returned to work on their normal hours with 1 in 6 (16 per cent) having returned on reduced hours. 1 in 5 (20 per cent) were on paid sick leave, with a small minority (3 per cent) being on unpaid sick leave.

Some respondents highlighted that they had felt forced to return to work full-time, when they would have preferred to have a longer and more flexible phased return. A common reason given was that the worker could not afford to reduce their hours.

I was told that a longer phased return could not be accommodated so if I didn't return full-time my contract would need to be changed to have less paid hours. I couldn't afford this so felt compelled to return full-time when I didn't feel ready to. Since returning full-time, I am never asked how I am and it seems that because I'm back at work I must be fine. In reality, I still struggle with several long Covid symptoms, only just able to get through a day at work.

Respondent working in Education sector, 36 – 45, female, key worker, Yorkshire and Humberside

Others stated that it was not physically possible for them to work full-time hours. One respondent described the financial impact of this, having been told by their employer that they would shortly have to move to full-time hours.

I have to go to full-time hours but physically I can't. I will have to go part-time and lose my house because I won't be able to afford the mortgage. I will be unwell if I try to do the hours.

Respondent working in Public safety and national security, 56-65, male, East Midlands

Communication with employer

Just over two-thirds of respondents (67 per cent) had informed their employer that they had long Covid. However, a quarter (25 per cent) had not.

Respondents were evenly split as to whether they had spoken to their employer about changes that could be made to help manage their job or return to work (49 per cent had spoken to their employer, 49 per cent had not).

Almost all of the workers that had not made their employer aware that they had long Covid (92 per cent) had also not talked to their employer about changes that could help them manage their job or return to work. for example in their hours or where they worked.

However, one in eight of those who had not told their employer they have long Covid were concerned it has affected how their performance will be assessed by their manager and one in 12 said they were concerned it has affected thier chances of a promotion in the future.

Changes made

Over two in five respondents (44 per cent) who talked to their employer about changes that could help them manage their job or return to work said all the changes they asked for had been made.

However, around three in 10 (31 per cent) reported that only some of the changes they asked for had been made, with one in 12 (8 per cent) reporting none of the changes they asked for had been made.

Respondents told us that in many instances, where changes had been made, the process of getting them put in place had been difficult.

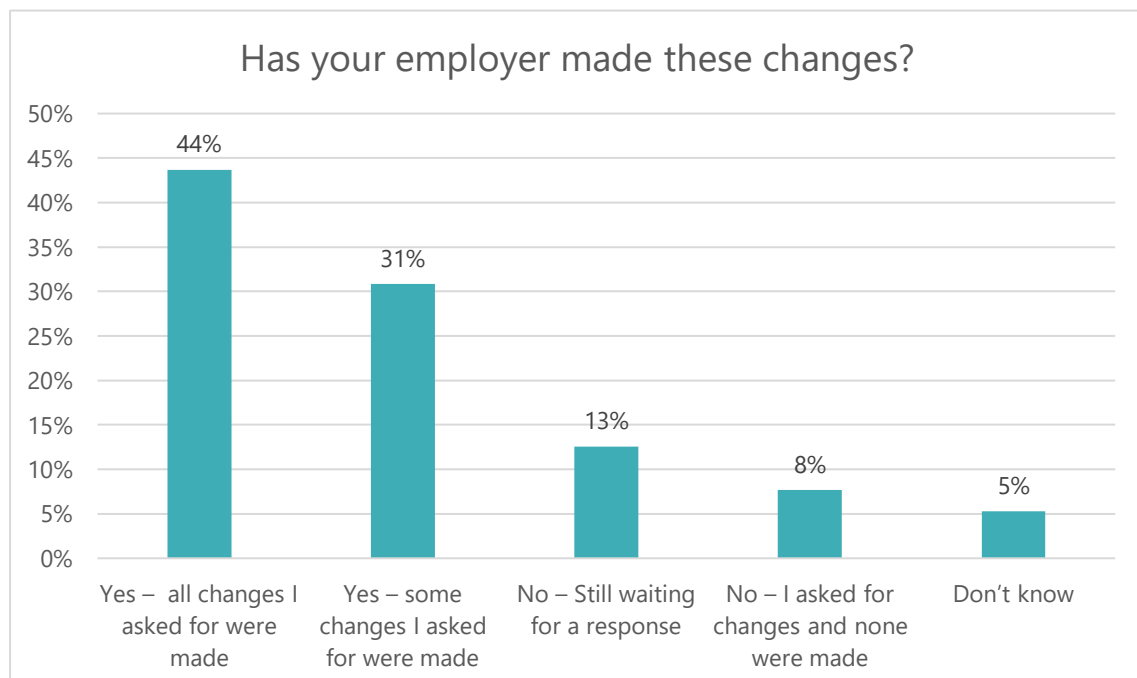
I had to go through a formal grievance process for my accommodations to be heard and considered.

Respondent working in Arts, Entertainment and Recreation, 26 – 35, female, Scotland

Had to involve occupational health and my own doctor before anything was done and this is still ongoing.

Respondent working in Public administration, defence and social security, 56 – 65, male, Key worker, North East

And one in eight (13 per cent) respondents had asked for a change and were still waiting for a response from their employer.



Changes asked for and put in place

We asked respondents which changes they asked for and which their employers had put in place.

In two categories, phased return to work and support from occupational health, more respondents had a change implemented than asked for it.

In all remaining categories fewer workers received a requested change than asked for it.

Requests for 'flexibility to support fluctuations,' 'longer/more frequent breaks' and 'amended duties' were among the most frequently requested changes and also ones with the highest discrepancy between being asked for and put in place.

What changes did you ask for and what changes did your employer put in place? Please select all that apply. ²			
	Asked for	Put in place	Difference
Flexibility to support fluctuations	53%	32%	-21%
Longer/more frequent breaks	42%	29%	-13%
Amended duties	48%	38%	-10%
Physical changes to the workplace	14%	5%	-8%
Flexi hours	37%	29%	-7%
Permanent hours change	15%	8%	-7%
Additional equipment	14%	8%	-6%
Different job	10%	5%	-5%
Ongoing home working	34%	29%	-4%
Changed workplace location	22%	18%	-4%
Temporary hours change	51%	50%	-1%
Phased return to work	56%	63%	6%
Support from occupational health	43%	49%	6%

Phased Return to Work

The most frequently asked for change was a phased return to work (56 per cent). This change was also the most likely to be put in place by employers (63 per cent). This shows that one in 16 respondents (6 per cent) who had this change implemented had not requested it.

² This table does not include those who responded by saying the change was not applicable.

Despite being both one of the most requested and granted changes to working patterns, many respondents noted they had experienced significant problems with phased returns to work, highlighting that they had to stop their phased return when their symptoms became more severe.

This aligns with what respondents told us about the fluctuating nature of long Covid with the vast majority (92 per cent) of respondents telling us that their long Covid symptoms varied over time, becoming worse on some days than others.

Respondents said:

I had shorter hours agreed but issues around workload and length of phased return meant three failed returns.

Respondent working in Public administration, defence and social security, 46 – 55, female, Key worker, Yorkshire and Humberside

I had a failed phased return. We did not have proper discussion about how my work would be managed when the phased return was over. As a result I ended up doing too much and made myself worse. I went back on sick leave.

Respondent working in Health and social work, 36 -45, female, Key Worker, Yorkshire and Humberside

Flexibility to support fluctuations in symptoms

The second most requested change (53 per cent) was for the employer to offer flexible working to support respondents' fluctuations in symptoms. However, even though this was one of the most requested changes, less than a third (32 per cent) of employers had put this change in place. This was the biggest gap between requests and provision (21 per cent).

Longer/more frequent breaks

Over four in 10 (42 per cent) requested longer or more frequent breaks to help them manage their job on their return to work. However 13 per cent of those who asked for this change to be made were turned down.

Amended duties

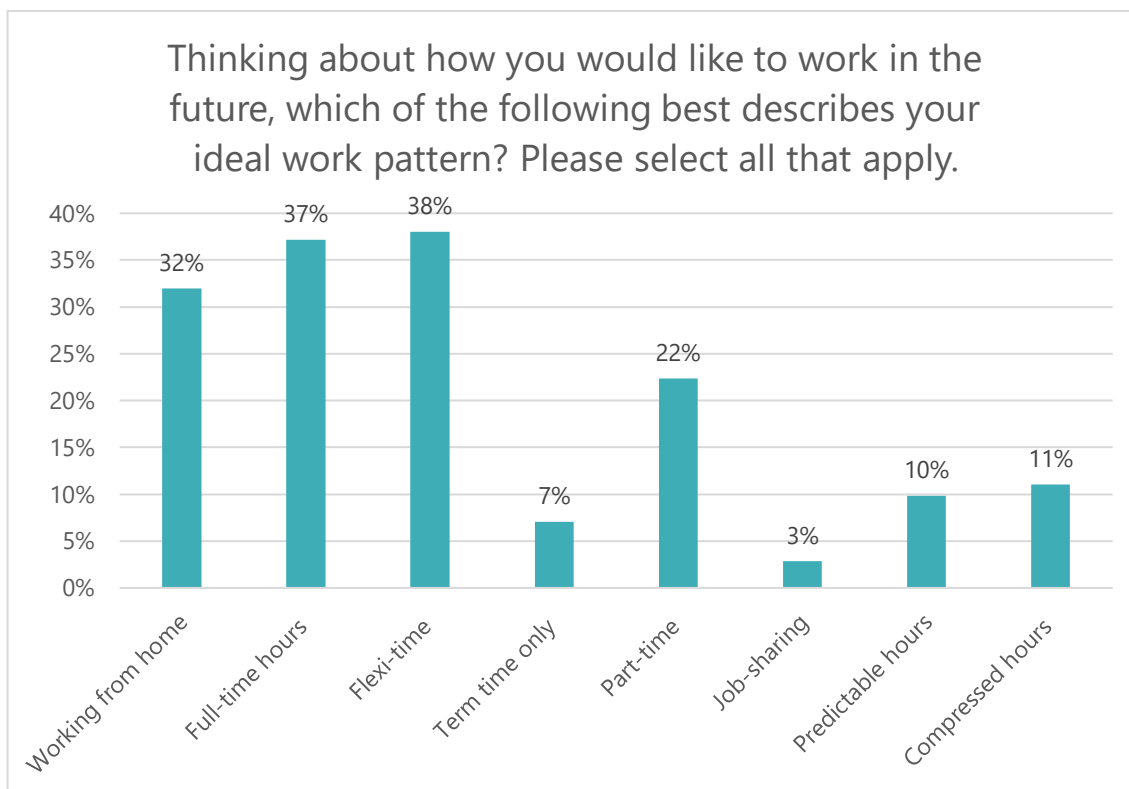
Almost half (48 per cent) of respondents asked for their duties to be amended which makes the requested change one of the most asked for. Of those who requested it 10 per cent were turned down.

Ideal working arrangements

We wanted to understand whether people with long Covid wanted flexible working in order to help manage their condition. Respondents were asked to think about how they would like to work in the future and to select the options which described their ideal working pattern.

More than a third (37 per cent) of respondents indicated their ideal working pattern was full-time hours, while just under a third (32 per cent) indicated they would like to work from home and almost four in 10 (38 per cent) indicated their ideal working pattern was flexi-time.

The fourth most popular working pattern, with over a fifth (22 per cent) selecting it, was part-time working followed by compressed hours (11 per cent), predictable hours (10 per cent), term time only (7 per cent) and job-sharing (3 per cent). More than four out of five respondents (83 per cent) said that they wanted some form of flexible working.



Treatment at work

To understand how long Covid impacted on workers' treatment at work we asked respondents if they had experienced different types of unfair treatment. Respondents were able to select all the types of treatment they had experienced.

Over half of respondents (52 per cent) selected one or more of the types of unfair treatment at work.

Performance

Over one in five respondents (22 per cent) told us they were concerned that having long Covid would affect how their performance will be assessed by their manager and over one

in six were concerned that having long Covid had affected their chance of a promotion in the future (18 per cent).

One in 14 respondents (7 per cent) told us their colleagues or managers had questioned their commitment to their job.

Disbelief

Just under one in five respondents (19 per cent) told us their employer had questioned the impact of their symptoms and one in eight (13 per cent) said their employer had questioned whether they have long Covid.

Over one in 17 respondents (6 per cent) reported that they were repeatedly asked for test results when unable to get tested.

Many respondents spoke of feeling as if they had to hide their symptoms at work and of the negative response of colleagues.

I feel like I have to hide my symptoms from some colleagues as they don't understand long Covid or think it exists.

Respondent working in the Civil Service, 36 – 45, female, North West

My line manager questioned if I had Covid as it was during the first lockdown. I have subsequently hidden my long Covid symptoms from him and struggle once I have left work at home.

Respondent working in Education, 56 – 65, female, Yorkshire and Humberside

I experienced disbelief and a lack of empathy or compassion. I was expected back to work after 14 days despite being very ill indeed. I took one week sick leave which was not covered by COVID exceptions (14 day max). I came back to work after 3 weeks and had a breakdown less than 4 weeks later because I was so exhausted and unwell. I had to take a further 4 weeks sick and moved to another job. At the time I had COVID March 2020 there were no tests available. It was horrible and still affects me emotionally because nobody believed me in work employer or colleagues.

Respondent working in Health and social work, 36 – 45, female, key worker, Northern Ireland

Sick leave and management action

Over one in six respondents (18 per cent) told us the amount of sick leave they had taken triggered absence management or HR processes and one in 11 (9 per cent) said they had used all their sick leave entitlement and had been told there would be negative consequences if they took more.

One in 25 respondents (4 per cent) said they had been forced to take additional unpaid leave as a result of having had long Covid.

One in 25 respondents (4 per cent) also reported being threatened with disciplinary action, while fewer respondents reported being subject to disciplinary action (1 per cent) and were subject to capability proceedings (3 per cent).

My sick leave triggered a health at work meeting but it was cancelled when my union rep stated that covid related sickness should not trigger normal absence policy.

Respondent working in Education, 46 – 55, female, key worker, disabled, West Midlands

I have had to use my annual leave to manage my symptoms. I have told my manager but because I look ok I don't think she appreciates how severely it has impacted my life.

Respondent working in the Civil Service, 46 – 55, female, key worker, disabled, South West

HR repeatedly questioned the length and appropriateness of my phased return despite support from my GP, manager and occupational health. Strongly suggested I needed to take annual leave to supplement phased return. Has made me reluctant to ask for additional flexibility and I worked after a flare up of symptoms after first vaccine.

Respondent working in Health and social work, 46 – 55, female, key worker, Yorkshire and Humberside

I felt forced to return to work to protect my income. I think I was about to be on half pay. I have been doing a phased return and now I am about to return to my normal working hours. I am worried I may struggle and do not want another absence on my record or my wage to drop.

Respondent working in Education, 36 – 45, female, Key Worker, Scotland

Job loss, redundancy, and retirement

A number of respondents highlighted the impact having long Covid had on their job security.

One in 20 (five per cent) said they were;

- forced to take early retirement
- forced to resign to protect their health
- forced to leave their job for other long Covid related reasons
- singled out for redundancy.

I have decided to retire due to my long Covid. I feel it's the only option I have to get better in the future.

Respondent working in Public administration, defence and social security, 56 – 65, female, Scotland

I had to stop working for the sake of my health, as over the months after my initial illness I got worse instead of better.

Respondent working in Health and social work, 36 – 45, female, key worker, Scotland

Poor treatment

Around one in 12 respondents (8 per cent) said they have been subject to bullying and/or harassment (for example being ignored or excluded, singled out for criticism or excessive monitoring of work) because of having long Covid. One in 25 respondents (4 per cent) reported being given harder to less popular tasks at work compared to other colleagues in a similar role/ level of seniority.

One in eight respondents (8 per cent) reported

- not having a pay rise when other colleagues have (2 per cent)
- being denied access to paid overtime when others have been able to access overtime (1 per cent)
- being moved to another job against their wishes (1 per cent)
- being given fewer hours/ shifts against their wishes
- being scheduled for less popular shifts (1 per cent)
- experiencing negative changes to other benefits (e.g. pension etc.) (2 per cent)

One in nine respondents (11 per cent) told us about other types of unfair treatment. This included:

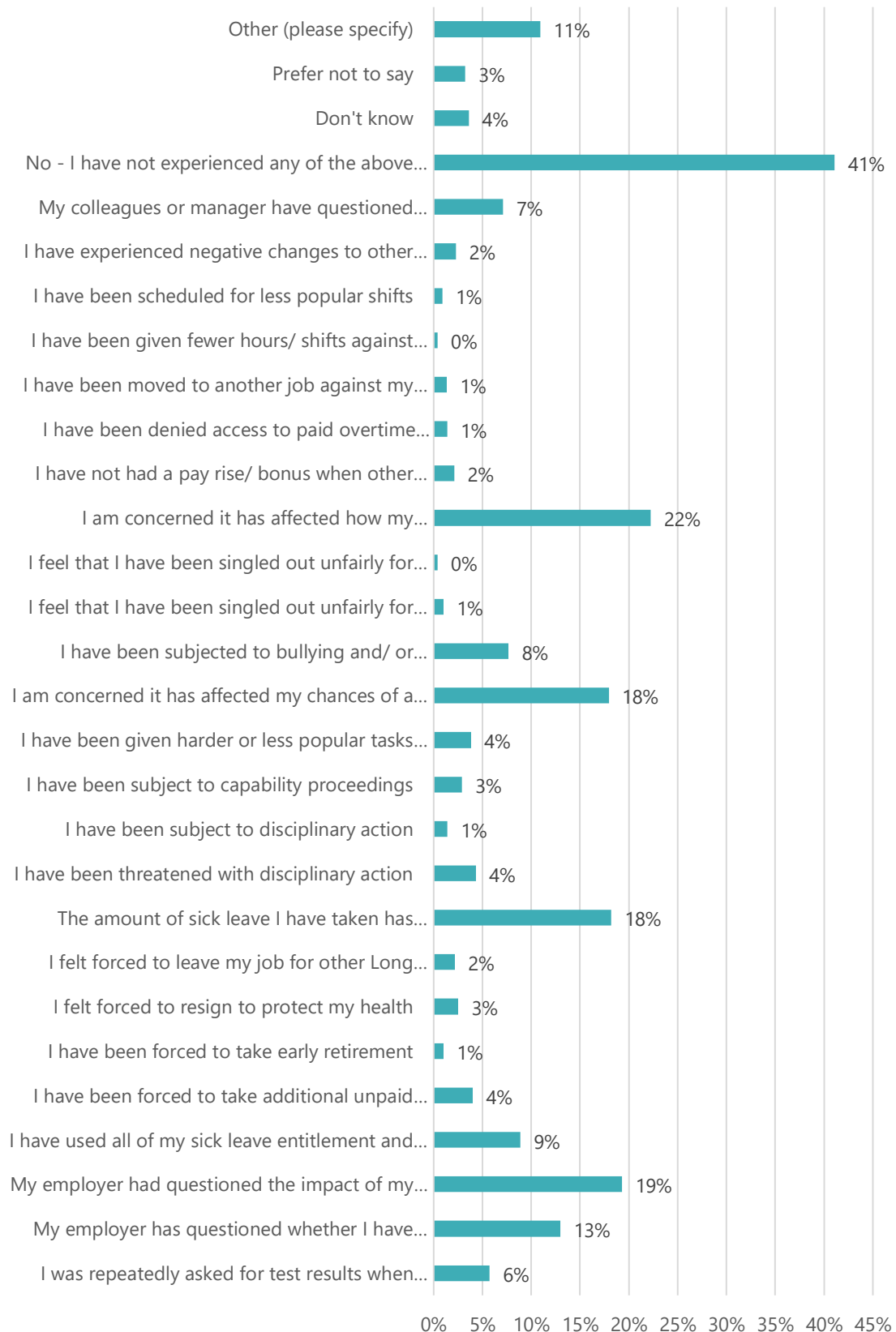
I have been threatened with dismissal and asked to pay back all money I received when off sick (from one manager not organisation).

Respondent working in Public administration, 46 – 55, female, South West

I have been told that I may have to sign a new contract for part time only hours if I can't get back up to full time in 8 weeks.

Respondent working in Utilities, 46 – 55, female, South West

Have you experienced any of the following as a result of having had long Covid? Please select all that apply.



Health and safety and workplace transmission

The TUC believes that workplaces have been a significant site of transmission of Covid-19. Covid-19 outbreaks in workplaces have been well documented throughout the pandemic. In 2020 alone, there were 4,523 outbreaks reported in 'workplaces' (excluding care homes, hospitals, education settings and prisons). This suggests that, in some settings, the likelihood of Covid-19 having been passed from person to person within their place of work is higher

Additional data also indicates a higher instance of occupational exposure in certain sectors, including the food service sector, retail and transport. An [ONS study](#) points to jobs where social distancing was not possible as a factor in why infection rates were so high. In hospitals and care settings, lack of access to suitable personal protective equipment (PPE) was raised by trade unions, particularly during the first 'wave' of the pandemic.

Issues concerning a lack of PPE were also raised by respondents to the long Covid survey who identified this as a direct causal factor in them contracting Covid-19 and long Covid.

One respondent said;

'I work as a Health Care Assistant in a hospital. During the pandemic we were low on PPE and therefore we were not provided with enough or the correct PPE as a result.

What constituted as the correct PPE changed constantly and seemed to depend on what was available. For weeks we were told that basic surgical masks were sufficient but as soon as they had more FFP2 or similar masks we were told that they must be worn... I caught Covid twice as a result of this...I had to sit with a confused, covid positive patient for ten hours wearing only a surgical mask and a basic white apron... The first time that I caught it, I was working on a ward which actually refused to give me a mask to begin with. Other wards were hiding/hoarding PPE. Since October I have been suffering with chest pain that has got gradually worse. I've had to take unpaid time off work and it has also negatively affected my personal life.'

Respondent working in Health and social work, 26 – 35, male, Key worker, East Midlands

A TUC poll found that less than half of workplaces had enabled social distancing, with only two-fifths (38%) of workers aware of a workplace risk assessment. The likelihood of being paid company sick pay (as opposed to Statutory Sick Pay) has also been identified as a contributing factor in likelihood of transmission, as workers reported not being able to afford to self-isolate.

While government-issued guidance gave employers advice on making workplaces 'Covid secure', it did not go far enough. The TUC raised concerns about the lack of risk assessment publication being mandatory, as well as a failure to address the risk of Covid-19 aerosols and airborne transmission. For example, advice from government departments and the Health and Safety Executive (HSE) on the importance of ventilation as a safety control measure came months too late.

The TUC has also raised concerns about the safety enforcement infrastructure. Both the HSE and local authorities have suffered significant funding cuts since 2010, reducing the number of safety inspectors and the number of pro-active inspections carried out. This left regulators ill-equipped to respond to a pandemic, relying on short-term funding paid to contractors to carry out unwarranted 'spot checks' on safety. The TUC's concern at the lack of enforcement notices being issued to employers is well documented. With just 0.1% of Covid-19 concerns resulting in an enforcement notice and no prosecutions, we remain concerned that a failure to take tough action against the worst offenders removes incentive for keeping workers safe.

It is expected that Covid-19 will be prescribed as an occupational disease, at least in certain sectors, as it is the case that for some workers, the likelihood of exposure to Covid-19 – and therefore long Covid – has been higher. Currently Covid-19 is considered a reportable disease under the Reporting of Injuries, Diseases and Dangerous Occurrences Regulations, however there is widespread under-reporting; and this does not qualify workers for any means of compensation.

Several states have classified Covid-19 as an occupational disease and established compensations schemes for frontline workers. According to the World Health Organisation: "Workers who are infected by Covid-19 as a result of their work should be entitled to health care and, to the extent that they are incapacitated for work, to cash benefits or compensation, as set out in the Conventions No.102 and 121." The Industrial Injuries Advisory Council is currently considering available data before making a decision on prescription of Covid-19 (and long Covid) as an occupational illness. This would mean classifying the disease as one linked to certain jobs; for example tuberculosis is a prescribed disease for healthcare workers who may become exposed at work. An IAC paper, published in March 2021, states: "evidence of a doubling of risk in several occupations indicates a pathway to potential prescription." This decision would be significant. It could mean long Covid patients would be eligible for Industrial Injury Disablement Benefit (IIDB), a form of financial support.

Experiences of key workers³

Almost eight out of 10 respondents (79 per cent) to the survey identified as a key worker.

In many areas the experiences of key workers was similar⁴ to the experiences of all the respondents. Considering the high level of key workers responding to the survey this is unsurprising.

Communications with employer

Key workers were more likely to make their employer aware they had long covid. (71 per cent compared to 67 per cent)

Changes asked for and put in place

Key workers were as likely as the full set of respondents to ask for:

- flexibility to support their symptoms but less likely to have the change put in place. (32 per cent compared to 29 per cent)
- flexi hours but less likely to have the change put in place. (25 per cent compared to 29 per cent)

Key workers were less likely to ask for ongoing home working (30 per cent compared to 34 per cent) and less likely to have it put in place (23 per cent compared to 29 per cent).

However, given the nature of many key workers roles where remote working is less likely to be an option, this difference is not surprising.

Ideal working arrangements

Key workers were less likely to say their ideal working pattern was:

- working from home (25 per cent compared to 32 per cent)
- flexi-time (35 percent compared to 38 per cent)

Key workers were more likely to say their ideal working pattern was:

- full-time working hours (40 per cent compared to 37 per cent)

Education

Over a third of respondents (34 per cent) to the survey told us the main business activity of the organisation they worked for was education.

³ Although no definition of key workers was provided within the survey the TUC defines key workers as workers who continued working outside the home throughout lockdowns and local restrictions. The majority of key workers such as those working in retail, education, and health and social care are in public facing roles putting them at higher risk of exposure to coronavirus.

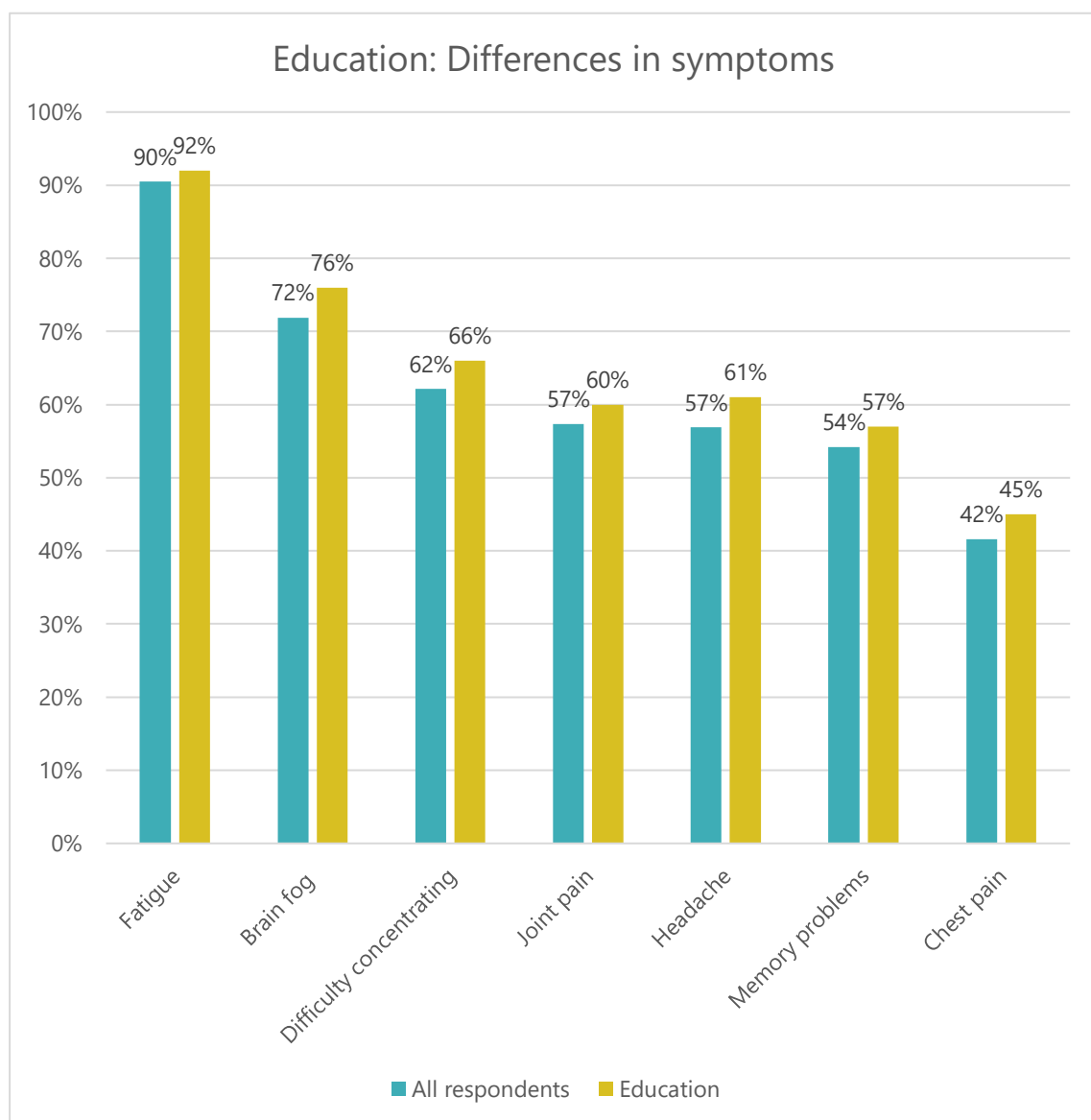
⁴ Within 2 per cent of the full set of respondents.

Government advice until August 2020 was that it was up to individual schools to decide if their children needed to wear masks in classrooms, corridors and communal areas.

Staff working in the sector raised concerns that they were discouraged from mask wearing and that adequate ventilation wasn't possible due to the nature of some school buildings. These safety issues put education workers at higher risk of catching Covid-19

In many areas the experiences of education workers was similar⁵ to the experiences of all the respondents.

Nearly all respondents who worked in education, 96 per cent, who told us that they had long Covid were currently experiencing symptoms compared to 93 per cent of all respondents.



⁵ Within 3 or 4 per cent of the full set of respondents.

Education workers experienced the full range of long Covid symptoms in line with that of the full sample of respondents.

However workers in education were less likely to say they'd returned to their usual hours than all respondents (54 per cent compared to 57 per cent) and slightly more likely to say they were on paid sick leave (23 per cent compared to 20 per cent).

They were also more likely to have made their employer aware of their long Covid symptoms with 74 per cent reporting they had done so compared to 68 per cent of all respondents.

Education workers were also less likely to have had all the changes they asked for made (41 per cent) compared to all respondents (44 per cent) and were;

- Less likely to ask for a different job (5 per cent compared to 10 per cent)
- Less likely to ask for flexi hours (32 per cent compared to 37 per cent)
- Less likely to ask for longer more frequent breaks (37 per cent compared to 42 per cent) but also less likely to have longer, more frequent breaks put in place (18 per cent compared to 29 per cent).

Education workers were more likely to say their ideal working pattern was to work term time only (17 per cent compared to 7 per cent) and less likely to say their ideal working pattern was

- Working from home (26 per cent compared to 32 per cent)
- Full-time hours (29 per cent compared to 37 per cent)
- Compressed hours (6 per cent compared to 11 per cent)

Education workers described their experiences:

I caught Covid from my work at primary school, where it's impossible to keep 2m distance. We were initially told 'masks are not necessary and they distress/worry the children so not to wear them' I was allowed to wear one after had Covid, but by then I had long Covid and had to go off sick as couldn't cope.

Respondent working in Education, 56 – 65, female, key worker, North West

I contracted Covid in school. A few weeks before I became ill my class absences were high, a lot of the children were absent with high fevers, sore throats and coughs which many parents now say was probably Covid. I subsequently became ill and was very unwell. Although I am doing a phased return and feel a lot better I am finding the fatigue really difficult and other symptoms such as headache, joint pain, cough are still there. Not as bad as it was but I'm still not 100% but I had no option but to return as I was going to end up on half pay and as I am part time this would not have been financially viable. I feel upset that I contracted this at work but have no financial support to allow me to recover properly.

Respondent working in Education, 46 – 55, female, key worker, disabled, Scotland

Prior to contracting Covid I had been covering a large class in the school full time. My head teacher told me that my only option to be in work every day covering children of key workers. There was no regular testing available to me even though I was in full time contact with children during the lockdown. I had to send for a home test and was told that I couldn't have any for close family members. Following symptoms, I self isolated for ten days. After six weeks I felt obliged to return despite not feeling better. I was back in a large class of 30 children. No back to work follow up meeting or check to see if I was okay, I've just been left to carry on as normal. ... my school... has a very strict absence policy and I was worried about taking any longer off.

Respondent working in Education, 46 – 55, female, key worker, Scotland

There is no question that I caught Covid in the workplace. During the pandemic, I went into school, left each evening and had no contact with any other human until I returned the next day, each and every day. My shopping was delivered and all cleaned. Petrol purchased through a debit card pump. Having pointed out to my employer I caught covid while at work, my employer disputes my claim. Long covid should be classed like a lot of other European countries as an occupational disease. I should NOT be held accountable for the sickness it has caused me and this sickness should not be on my employment record at my detriment. My employer talks about the impact my illness has had in the school but does not consider the impact, perhaps long term that having caught covid in the workplace has had upon my quality of life. I feel very aggrieved at the pressure my employer is placing upon me. I feel disabled by long covid and not the person I was before it. My employer is rigidly sticking to an absence policy and procedure which does not reflect covid or long covid and there seems a lack of any support, guidance or legislation from the government. I fear now that my sickness pay will be significantly reduced and I have already seen a reduction in month 6.

Respondent working in Education, 46 – 55, male, Key worker, Wales

I do my best to teach my class but really struggle with fatigue as a result. This means I am unable to do my normal home tasks like cooking, cleaning etc when I come home from work as I have no energy. I fall asleep on the sofa and feel like I have no other life apart from work. I'm struggling with the planning for lessons and the paperwork. I would like my employer to reduce the amount of paperwork until my symptoms ease up as if I have to keep going with things as they are now I will have no choice but to take days off work to deal with the fatigue that I'm feeling.

Respondent working in Education, 46 – 55, female, Key worker, Northern Ireland

Health and social care

Just under three in 10 respondents (28 per cent) to our survey worked in health and social work.

Health and social care workers reported experiencing long Covid for similar lengths of time as the full set of respondents; however they were more likely to say they had long Covid symptoms for 12 months or longer. (38 per cent compared to 29 per cent)

Health and social care workers also reported experiencing symptoms of long Covid at a higher rate than the full sample of respondents across all 21 symptoms except for depression which they experienced at the same rate.

The biggest difference was in reports of 'Fast-beating or pounding heart' where health and social care workers reported 13 per cent higher than the full sample (59 per cent compared to 46 per cent). The second highest difference was in reports of muscle pain which was 11 per cent higher (64 per cent compared to 53 per cent).

Health and social care workers were also less likely to have returned to work on their usual hours compared to the full set of respondents (40 per cent compared to 57 per cent) and more likely to be on paid sick leave (36 per cent compared to 20 per cent). However, given the nature of the roles, remote working is less likely to be an option, so this difference is not surprising.

Workers in health and social care were more likely to have made their employers aware they had long Covid symptoms. (83 per cent compared to 68 per cent) and to have talked to their employer about changes that could help them manage their job or return to work. (60 per cent compared to 49 per cent). The changes they asked for and were put in place were similar to those of the full set of respondents.

Health and social care workers' experiences

Respondents working in Health and social care talked about lack of adequate PPE, lack of social distancing and the public-facing element of their work that put them at higher risk of contracting the coronavirus.

They have refused to accept or acknowledge I have long Covid because when I got sick we didn't have COVID tests so I wasn't able to produce a test result, despite OH even stating I have all the symptoms. No support has been put in place. I would like them to acknowledge it and mark it as long Covid against my sickness.

Respondent working in Health and social care, 36 – 45, female, Key worker, South West

I constantly felt unsafe whilst working during all lockdowns. I made complaints to 4 levels of senior management to complain about being put into unsafe and risky situations without any care of workers health concerns . I have worked for this local authority for 30 years . My colleagues were not informed I had contracted Covid nor was I informed that infection was identified in our area offices . I was forced to use public transport and see clients in public spaces as we had no office space offered to us to see clients there . I have been very unwell and feel both sad and upset that I then infected family members and both my partner and daughter have been adversely affected also.

Respondent working in Health and social care, 56 – 65, female, Disabled, key worker, South East

I'm a nurse and probably contracted Covid from the wards. It's policy that Covid not fall into the normal sickness staging, however HR are questioning the validity of my diagnosis, even though my fit note states long Covid, I was referred to the long Covid service and am now receiving treatment. I am still being treat as long term sick and the worry of losing my job is having a detrimental effect on my overall well-being. It's disappointing considering I'm employed by the NHS.

Respondent working in Health and social care, 46 -55, female, Key worker, North West

I was a frontline NHS worker who was affected early in the pandemic. All the while people were saying my colleagues were 'heroes', I ran out of sick pay, couldn't afford my rent, lost my home and had to resign my job as I had to move away to stay with family until I recover. I'm now on benefits. Throughout the pandemic I have felt abandoned by the society who were applauding people who were facing the virus that destroyed my life. The NHS needs to be in a better position to support its workers who contract the virus trying to keep the rest of the nation safe.

Respondent working in health and social care, 36 -45, female, Key Worker, South East

I am in my late 50's , and feel I have aged 20 years with joint problems .If these problems carry on I will not be able to carry on until I am 67 years for the state pension . It was not my fault I got Covid. I went to work with no PPE and it has given me a life of disability and pain. I have given 30 years to the NHS. Before Covid I climbed Snowdon, now I find it hard climbing the stairs.

Respondent working in Health and social care, 56 – 65, female, Key worker, North West

I got covid from work (I'm a nurse) and ended up in intensive care on a ventilator for 40 days. I returned to work 8.5 weeks after discharge from hospital after 9 weeks despite struggling with reduced hours on my phased return they were expecting me to be back to full time within a month and my consultants at post covid follow up felt work was impeding my recovery. I was expected to have virtual hospital appointments or GP phone appointments from work and go to work before or after face to face hospital appointments despite it taking me up to 1 hour to travel between my work and site of the appointment. Despite knowing how ill I had been the other members of the team were taking unnecessary risks by not using PPE or correct PPE when doing aerosol generating procedures on patients who had not been covid tested prior to procedure and turned out to be positive.

Respondent working in Health and social care, 26 – 35, female, Disabled, Key Worker, Scotland