The economic impacts of Long COVID in the UK: A qualitative pilot study

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1. Introduction

Recent research[1] has highlighted the significant economic impacts of Long Covid, with over half those affected working reduced hours, with many needing informal care support from friends and family and an average cost (in terms of work lost) of over £10,000 per person. This project, a collaboration between the School of Geography and the Environment (SoGE) and the charity Long Covid Support (LCS), aimed to provide insights into the stories behind these numbers through 10 in-depth interviews with people with Long COVID, and a further two interviews with advocacy organisations involved in supporting them. Interviews were analysed and inductively coded to draw out key themes and concerns. The report below summarises the background to the project, the methods used and the key project findings, which include peoples' experiences of work and the benefits system after contracting Long COVID, as well as the increased costs and financial strains they faced.

The research was supported by Oxford UNIQ+ summer internship programme[2], which gives talented undergraduates from under-represented groups across the UK the opportunity to experience working within an academic research environment.

[1] Long Covid Support (2025) Long Covid Status Report https://www.parallelparliament.co.uk/files/appg_documents/long-covid/Status_Report_by_Long_Covid_Support_for_the_APPG.pdf
[2] https://www.ox.ac.uk/admissions/graduate/access/uniq-plus

2. Background

Long COVID is a chronic condition which occurs following infection with Severe Acute Respiratory Syndrome coronavirus 2 (SARS-CoV-2). Over 200 symptoms across multiple organs have been identified,[3] with more common ones including cognitive impairment, fatigue, shortness of breath, heart palpitations, joint and muscle pain, and impacts on the gastrointestinal system. Long COVID has been shown to lead to other conditions, including an increased risk of cardiovascular issues[4] and diabetes[5].

Over 65 million individuals worldwide are estimated to have long COVID[6] and in the UK alone recent estimates suggest Long COVID affects 1.8% of the population[7]. The impact on the quality of life of individuals affected is significant. In terms of the HRQoL (Health Related Quality of Life) the condition is on par with the burden of Parkinsons and cancer[8]. Current diagnostic and treatment options are limited[9] and the specialist treatment options provided during the pandemic such as Long COVID clinics have been closing, with only 34 likely to remain operational as of April 2025 down from a peak of 104 services in 2022.[10] Due to the limited availability of diagnostic and treatment options, it is common for out-of-pocket payments (OOPPs) to be used in financing care, especially physical therapy, diagnostic tests, and dietary supplements.[11] The prevalence of OOPPs is further exacerbated by insurers aversion to insuring individuals with chronic illness due to their high risk profile. Patients and health care providers have identified a pressing need for further research and guidance on managing Long COVID, and advocate for improved collaboration and coordination between healthcare providers to address the complex needs of Long COVID patients.[12]

Existing studies have sought to quantify the economic impacts of Long COVID. In the UK, Kwon and colleagues surveyed patients who had been referred to Long COVID clinics and found that 51.7% had reduced their paid working hours relative to pre-infection and the mean monthly income of the cohort had declined by 24.5%. They further estimated that scaled up to the UK population as a whole this equates to an overall loss of productivity since infection of around £5.7 billion[13], with the additional productivity loses (estimated at £4.8 billion) incurred when friends and family give up paid

[3] Davis, H.E., McCorkell, L., Vogel, J.M. et al. (2023) 'Long COVID: major findings, mechanisms and recommendations.' Nat Rev Microbiol. 21, 133–146 https://doi.org/10.1038/s41579-022-00846-2

[4] Xie, Y. et al. (2022) 'Long-term cardiovascular outcomes of COVID-19', Nature Medicine, 28(3), pp. 583–590. Available at: https://doi.org/10.1038/s41591-022-01689-3.

[5] Wong, R. et al. (2023) 'Does COVID-19 Infection Increase the Risk of Diabetes? Current Evidence', Current Diabetes Reports, 23(8), pp. 207–216. Available at: https://doi.org/10.1007/s11892-023-01515-1.

[6] Davis et al 2023.

[7] Greenhalgh, T., Sivan, M., Perlowski, A., & Nikolich, J. Ž. (2024). Long COVID: a clinical update. Lancet (London, England), 404(10453), 707–724. https://doi.org/10.1016/S0140-6736(24)01136-X

[8] Al-Aly, Z. et al. (2024) 'Long COVID science, research and policy', *Nature Medicine*, 30(8), pp. 2148–2164. Available at: https://doi.org/10.1038/s41591-024-03173-6; Walker, S. et al. (2023) 'Impact of fatigue as the primary determinant of functional limitations among patients with post-COVID-19 syndrome: a cross-sectional observational study', BMJ Open, 13(6), p. e069217. Available at: https://doi.org/10.1136/bmjopen-2022-069217.

[9] Al-Aly et al 2024; Greenhalgh, T. et al. (2020) 'Management of post-acute covid-19 in primary care', BMJ, p. m3026. Available at: https://doi.org/10.1136/bmj.m3026.

[10] Long Covid Support 2025.

[11] Scheel-Barteit, J., Floto, C., Höpfner, H. et al. (2025) 'Financial burden of patients with post-acute COVID-19 syndrome.' J Public Health (Berl.) Available at: https://doi.org/10.1007/s10389-025-02522-0

[12] Sunkersing, D. et al. (2024) 'What is current care for people with Long COVID in England? A qualitative interview study', BMJ Open, 14(5), p. e080967. Available at: https://doi.org/10.1136/bmjopen-2023-080967.

[13] Kwon, J. et al. (2024) 'Impact of Long COVID on productivity and informal caregiving', The European Journal of Health Economics, 25(7), pp. 1095–1115. Available at: https://doi.org/10.1007/s10198-023-01653-z.

work to act as informal carer givers.[14] At a global scale, Al-Aly *et al.* cite an estimated overall economic impact of around $1 trillion—or around 1% of the global economy.[15]

Qualitative studies have examined the experiences of people with Long COVID returning to work in Belgium[16] and the UK[17], with a particular focus on healthcare workers. These studies highlight the challenges of adjusting existing roles and schedules to fit with the demands of a dynamic illness like Long COVID, and the significant differences in the levels of support individuals received from co-workers, managers, occupational health teams and workplace health schemes. Furthermore, these studies highlight how the burden of informing the workplace as well as line managers was often placed on the person with Long COVID. Our study sought to complement and extend this work, considering not only the challenges people faced when trying to return to work, but also the consequences of not being able to return to fulltime work and associated loss of income.

3. Methodology

This study adopted a qualitative approach, seeking to understand how some of the larger economic trends outlined above were experienced on an individual level through in-depth interviews with those affected and with those who support them. Given this was a small-scale project (which needed to be completed within the 6-week internship period) the sample size was relatively small. Overall, we completed 9 online semi-structured interviews and one email interview with people with Long COVID and 2 interviews with people that are working at charities that support individuals with Long COVID. Table 1 provides a summary participant information extracted from interviews with people with Long COVID. The majority of our participants were female (8/11) and worked in the public sector at 9/11, as has also been common in other research[18]. Participants were recruited through our partners at Long Covid Support, using social media, which has both benefits in being both effective and efficient[19], as well as making research accessible to those with chronic illnesses, but which may also lead to self-selection bias. We would therefore recommend that additional research, ideally using a range of different recruitment methods, is undertaken to better explore how variables such as gender and employment may shape the economic impacts of chronic illness.

[14] Kwon et al 2024.
[15] Al-Aly et al 2024.
[16] Kohn, L. et al. (2024) 'Long COVID and return to work: a qualitative study', Occupational Medicine, 74(1), pp. 29–36. Available at: https://doi.org/10.1093/occmed/kqac119.
[17] Nielsen, K. and Yarker, J. (2024) '"It's a rollercoaster": the recovery and return to work experiences of workers with long COVID', Work & Stress, 38(2), pp. 202–230. Available at: https://doi.org/10.1080/02678373.2023.2286654.
[18] Buttery, S. et al. (2021) 'Patient symptoms and experience following COVID-19: results from a UK-wide survey', BMJ Open Respiratory Research, 8(1), p. e001075. Available at: https://doi.org/10.1136/bmjresp-2021-001075; Fang, C. et al. (2024) '"I am just a shadow of who I used to be"—Exploring existential loss of identity among people living with chronic conditions of Long COVID', Sociology of Health & Illness, 46(1), pp. 59–77.
[19] Leighton, K. *et al.* (2021) 'Using Social Media and Snowball Sampling as an Alternative Recruitment Strategy for Research', *Clinical Simulation in Nursing*, 55, pp. 37–42.

Table 1: Summary of participant information extract from interviews; [-] indicates missing data; LCAP05 and LCAP10 are interviews with advocacy organisations so are not included in this summary.

Identifier	Gender	Employment status pre long COVID	Employment status post long COVID	Housing status	Benefits	Dependents	Informal care
LCAP01	Male, 31	Self-employed film maker	Unable to work more than a few hours per week	Rented flat	Disability benefit (probably PIP)	None	Financial and care support from family
LCAP02	Female	Employed, full time teacher	Currently unable to work	Partner owns house	Disability benefit (probably PIP)	None	Support from partner
LCAP03	Female	Employed, full time civil servant	Currently on phased return to work	Own home with mortgage	PIP application declined	None	Support from husband
LCAP04	Male	Training to be a counsellor	Currently unable to work	_	PIP	Daughter	Support from wife
LCAP06	Female, late 40s	Manger at a small charity	Does small amount of admin for husband's business	Own house with mortgage	PIP, employment support allowance	3 older children, supporting one at university	Support from husband
LCAP07	Female	Employed, full time emergency medicine	Currently unable to work	Had to sell house	Pip and industrial injury benefit, has had employment support allowance in the past	Daughter	Husband sends maintenance payments for daughter
LCAP08	Female	FT employed civil service	Currently in FT work but thinking they will have to reduce their hours.	Living with parent	Has tried to apply for PIP but not yet managed to complete application	None	Support from parent
LCAP09	_	PhD student	Studying part-time	Renting	Applied for PIP	None	Support from family
LCAP11	Male	Working FT in IT	Made redundant. Currently looking for work	Own home with mortgage, planning to sell and downsize	Applied for employment support allowance	_	_
LCAP12	Male	FT employed in finance	On long term sick leave	Renting	Employment support allowance	None	Some support from parents

All participants gave their informed consent before participating. All names and other identifying information have been anonymised to protect the identities of those interviewed, although notably many were willing to be named if this might help raise awareness of the issues and challenges they and others like them faced. Ethical approval was granted by the University of Oxford's School of Geography & the Environment (SoGE) Departmental Research Ethics Committee (Reference 1929038). Interviews were planned and structured with advice from our collaborators at Long COVID support, including regular breaks and the potential for adjustments (such as rescheduling or completing the interview via email) to accommodate participants' diverse health needs. Participants were offered a £25 gift voucher or donation to a charity of their choice to thank them for their time.

The interviews were conducted over the Microsoft Teams platform which enabled us to record and transcribe them with only minor corrections to the transcripts being applied manually. All transcripts were pseudonymised by removing names and other identifying characteristics. Transcripts were coded and analysed using NVivo software and a blend of etic (following the structure of the questions) and emic (allowing themes to emerge from the data) codes. Members of the research team coded the transcripts individually before coming together to create a shared framework.

Table 2: Outline of the coding framework

Lead code	Sub Codes
Work	Impact on job prospects Inability to work Change of work responsibilities Desire to work Need to keep up professional appearances Reasonable adjustments at Work Discrimination at Work Lack of support at work
Housing	Cutting down on heating and electricity usage Type of housing Housing loss
Support	Family/Partner Support Charity/Non-Governmental support Lack of financial support Lack of public recognition/support
Extra-spending	Non-medical Medical
Emotions	Loneliness Dread I'm feeling lucky/privileged
Benefits	Easy access to ESA [Employment Support Allowance] Easy access to PIP [Personal Independence Payment/Disability Benefit] Easy access to UC [Universal Credit] Difficulties with PIP workers Difficulties with UC workers Difficulties with accessing PIP Difficulties with accessing ESA Difficulties with accessing UC
NHS Support	Inadequate NHS Support Medication Long Covid Clinics Lack of cure or treatment Lack of medical recognition
Mitigation	Self-medication Pacing Support Groups/Social Media Drug trials
Family Situation	Relationship Struggles Supporting a dependant
Physical Health	Reinfections Physical Restriction

4. Analysis

Our findings summarised below are divided into four main categories arising from our analysis of the interview transcripts: (i) impact on participants' work; (ii) experiences of applying for benefits; (iii) the additional costs of being chronically ill; (iv) the resulting financial strain experienced by participants' households.

4.1 Work

> *I feel robbed. I feel robbed by long COVID of my ability to work. (LCAP04)*

For all our participants their working lives had changed significantly. They found themselves having to take on different working responsibilities, move to part-time roles (with associated reductions in pay), accept a change of life plans or leave roles completely. It is notable that out of the ten participants listed in table 1, only one was still in full time work, and even they were uncertain how long they could sustain those hours. These changes were not instantaneous, rather most participants detailed a long period of transition. For some this involved returning to work following participation in government backed schemes to support workers during the Covid-19 Pandemic (such as furlong) or following a long period of working from home. For others it involved attempting phased returns to work or attempting to transition to a new (often more desk-based) role only to find this triggered a relapse or worsening of symptoms:

> *I was off work long term sick for two-and-a-half years from the initial infection, other than a couple of shifts. Like I said, at the four-week mark I returned back to work on a phased return, like two hours a week […] working from home […] alternative duties and I increased that to about ten hours and then I attempted another role, but that collapsed. I couldn't maintain that. (LCAP07)*

> *So yeah, then it just became a kind of a slow process of they would keep pushing to, you know, try and increase hours and realistically, over that next year and a half, we kept, you know, bumping up hours. And all it was doing, (with hindsight is very obvious now, but wasn't really obvious at the time), was just reintroducing more boom-and-bust cycles. So, you know, HR becomes increasingly frustrated […] you seem to be taking a lot of absences. Well, the problem is I start to do a bit more and then you crash out for a week or two with recovery. (LCAP10)*

Their feedback highlights the challenges of balancing the requirements of paid work, especially with respect to timelines and deadlines, and the demands of a dynamic illness such as Long COVID, which makes it hard to predict when you will be well enough to work and for how long. This is particularly challenging for those who are self-employed:

I do a bit of freelance writing, not paid just to keep busy, but the problem is […] I can't reliably work if I do a day, then the next day is bad. And as a self-employed person you let people down and then they stop asking. (LCAP01)

Those not self-employed experienced a range of different responses from employers. Some found themselves simply challenged through procedures for long term sick leave or dismissal on medical grounds. As one participant put it: '*My employer was very - umm - hands off and contractual about the situation*' (LCAP11). Others found their employers understanding and willing to make the adjustments they needed (at least initially), such as allowing them to work from home or on a more flexible, part-time basis. However, one theme that was continually present was a lack of broader understanding from colleagues and management about the chronic nature of Long COVID:

I had been with my employer for a long time and so had built up a good relationship with them. I felt there was a willingness to support me (e.g. they were very flexible with me working reduced hours in the early months of my illness). However, I do think there was (and is) a lack of knowledge about the condition, its impact, and how that might be managed within the work environment. (LCAP12)

My line manager's line manager […] he has a family member with Long COVID so very much understands, but I do think you need someone to have that almost knowledge to understand because it's not like a broken leg that will eventually get better. It's very much a long-term management strategy. (LCAP03)

Some spoke of direct discrimination arising from their illness. Others did not experience direct discrimination but spoke of how their new roles or adjustments made them feel they and their skills were less highly valued than before their illness:

I haven't faced discrimination in my current role because of being disabled.
I feel lucky for that. I think I have - like - a decent manager. But since asking to go part-time I've noticed a shift in the kinds of tasks that I get given to do, so things that we had previously agreed that I would like lead on over the summer have now been - like - taken away or changed and it makes me feel like they have less faith in me. (LCAP08)

We sort of agreed on an approach of - it feels horrible to admit that - but the bare minimum in order for me to write a thesis that will hopefully pass, but I'm not able to do any more than that. (LCAP09 – a PhD student)

Participants were keen to stress that it was not the case they didn't want to return to work. Indeed, for many the fact they could no longer pursue the careers they trained for or do the jobs they loved added to the burden of Long COVID:

'I have been teaching about five or six years and I was in a new school. I'd moved the September before I caught the COVID. And yeah, absolutely loved it. Like a lifelong dream. I miss it terribly.' (LCAP02)

The inflexibility of the benefits system (on which more below) was also a challenge. Participants described potentially being physical able to take on more work but also being reluctant to do so for fear it would impact the benefits they relied on for support.

4.2 Benefits

> *It's hell applying for PIP. It's extremely tiring. It took me a couple of weeks to fill in the PIP application form. It required me to, you know, real terrible levels of fatigue and it's quite humiliating. The level of detail that you must submit, you must submit like doctor's letters. The level of detail in terms of like things like your ability to wash and look after yourself and stuff. (LCAP04)*

Depending on their work and domestic situation our participants were potentially eligible for a range of different benefits, from private income and health insurance policies either accessed through employers or privately held, to government schemes. Some (whose Covid-19 infection could reasonably be linked to their work) had also received Industrial Injuries Disablement Benefit (IIDB). State benefits our participants identified included the Employment Support Allowance (ESA) and Personal Independence Payment (PIP) (see table 3).

Table 3 – Summary of the main kinds of UK state benefits our participants had applied for. Data was taken from www.gov.uk and correct at time of publication but may be subject to change in the future.

Universal Credit	Basic unemployment benefit for those out of work or unable to work. Monthly allowance of between £338 (for an individual under 25) and £666 (for a couple over 25 and living together).
Personal Independence Payment (PIP)	A scheme offering help with living costs for those with a long-term physical or mental health condition or disability. Monthly payments of around £400-800.
Employment Support Allowance (ESA)	A scheme offering money and support with living costs and access to work for those with a disability or health condition which effects how much they can work. A weekly payment of between £95 and £146.
Industrial Injuries Disablement Benefit (IIDB)	A scheme to compensate people who become ill or injured while at work or on an employment training scheme or course. A weekly payment of between £46 and £233 depending on the level of injury.

As with work, participants had a range of experiences of applying for benefits. Some had yet to apply, due to both concerns over the complexity and stress of the application process, but also a sense that applying for benefits is seen as something that is a last resort, reflecting the stigma they see associated with receiving benefits:

> *I've tried to apply twice. I've not completed the form so it stopped at that point […] I think there's two factors in it. I'm like scared about the application process. I'm scared about being interrogated and having to justify and like go in depth about like what is going on [… and also] I don't want to be a person who needs to be on benefits because of that illness. I think it is something that is taking a while for me to accept that it's probably needed and necessary, but it's a challenging - like - personal notion about how I see myself. (LCAP08)*

Furthermore, there was uncertainty over which benefits participants were able to apply for. One participant mentioned they had to reach out to the Citizen's Advice Bureau to understand what they are entitled to, while another relied on information shared by a contact who had experience working with charities that help people access benefits. A representative from an advocacy group described how people with Long COVID, like others, are increasingly turning to benefits to make ends meet:

> *Financial insecurity is more of a driver for people claiming disability benefits now that than at any one time...the social safety net is so tattered and benefits were frozen for a long time, so there's more of an incentive to look to the additional income streams. (LCAP05, interview with advocacy group representative)*

Once they did decide to apply for benefits, again participants had mixed experiences. Some had found the process for applying for ESA, for example, fairly straightforward (LCAP06). However, for the majority who had applied for Personal Independence Payments (8 of our 10 participants) the application process was lengthy, challenging, upsetting and frustrating:

> *It was a stressful process to apply, even though I knew it would be, I reacted worse than I thought I would to writing everything down and reading it back and … (LCAP09)*

Most participants found that it took them weeks to fill out the form for the PIP application. They described how the form had to be handwritten, particularly challenging for many people with Long COVID have who have limited energy and suffer from cognitive impairment. Most participants relied on support from their family and friends to fill out the application as they found it too difficult to do it by themselves.

When asked about recommendations on what can be changed and how to support patients with Long COVID their suggestions were to allow for the application to be submitted online. One of the advocacy organisations we spoke to suggested there was also a need to help applicants 'speak the language' of the benefits system to translate their application into categories and terms the Department of Work and Pensions assessors can recognise (LCAP05, interview with advocacy organisation). Getting the right kinds of medical evidence was also challenging given the lack of a straightforward diagnostic test for Long COVID, with some participants resorting to private healthcare to get the evidence they needed. Participants observed they found the form's questions ill-suited to the dynamic nature of their illness[20]:

> *The questions and determinators for ESA are in my opinion completely inappropriate for conditions such as Long COVID where symptoms can vary hugely day-to-day and where overdoing things can have a significant and detrimental effect on health. (LCAP12)*

> *I think one thing they could do with the PIP application processes is about the questions. The questions in the PIP application process don't reflect Long COVID at all. The questions in the PIP application process reflect what your level of disability stops you*

[20] Compare Lowe, J. and DeVerteuil, G. (2020) 'Austerity Britain, poverty management and the missing geographies of mental health', *Health & Place*, 64, p. 102358. Available at: https://doi.org/10.1016/j.healthplace.2020.102358.

from doing, but it doesn't really address the kind of chronic illness […] like long COVID or ME CFS or fibromyalgia or Endometriosis. It doesn't really reflect the kinds of things that those fluctuating conditions can stop you from doing. (LCAP04)

Once they had completed their applications, participants found themselves having to navigate a system where many of those they encountered seemed hostile and unsympathetic. While some participants spoke positively of their assessors, many participants expressed general feeling of not being listened to and described the assessment interview as feeling like an 'interrogation'. One participant described their experience with trying to claim Universal Credit (having not been deemed eligible for PIP):

I kept asking could I have a home visit and this guy on the phone kept saying "No, you can't have a home visit. That's not something we do." Which I later found out is not true, but they wouldn't allow me a home visit. This guy basically accused me of lying on the phone, he was basically like "you seem like a healthy person". (LCAP01).

The picture emerging is one where barriers to entry are both built into the bureaucratic processes of benefits administration and exacerbated by the challenges of communicating the experience of a complex, dynamic, long-term illness like Long COVID to benefit assessors. For example, one participant described how the report from the assessment did not accurately reflect what they had discussed with the assessor. Another described going through a tribunal to challenge inaccuracies in the report that was made on their condition. Similarly, one of the representatives from an advocacy group shared that they *'see some absolutely horrific decisions where really ill people are found to be to be able to function really well'* (LCAP05 – advocate interview).

4.3 Extra Costs

In addition to loss of income, people with Long COVID described new and rising costs associated with managing their condition. While some had been referred to Long COVID clinics, many found these failed to meet their needs and instead turned to private healthcare and complementary and alternative medicine, including treatments such as physiotherapy, mental health therapy, float tank sessions and hyperbaric chambers. Often these incurred significant additional costs:

I'm paying £300/£400 a month in supplements, just in case they help […] at one point in my early journey I was paying £1000 a month or £1000 every three months to a private doctor. (LCAP01)

Our participants recognised that their desire to find anything that would help improve their symptoms made them vulnerable to online marketing:

I feel way more susceptible to advertising in a way that I never did before. I have spent money on things that are, like, tangentially related to improving your health and your life because I've had such trouble getting any help from the NHS. I feel like I need to do things to try and, like, improve my situation. (LCAP08)

Further additional costs were incurred in the form of mobility and other aids, as well as adjustments made to homes and vehicles to accommodate changes to energy levels and mobility. For example, two participants had had to buy wheelchairs for themselves due to the inability to walk for extended distances. Here one of our participants lists how these aids – and their costs – added up:

> *like aids around the house, - like - to have a seat in the shower […] various bits and pieces, like to help my legs, adjustments for - like - vehicles or things like that. And we changed a vehicle of ours so that I could fit my - like - wheelchair and scooter in to have ramps and things like that. So that was quite a big, quite a big outgoing as well. (LCAP02)*

Almost all participants mentioned spending more on things such as masking, testing and air filters to avoid further reinfections. This extra spending increased due to the NHS stopping free Covid-19 tests.

Participants further described increased costs in both accessing public transport and using their private vehicles. Not being able to walk long distances led to having to park closer their destination which often incurred higher costs. Some described having to use more expensive modes of transport and/or pay for overnight stays because they did not have the energy to do long journeys without a break:

> *I can only drive short distances so am now reliant on public transport in a way I wasn't previously. Public transport costs are much higher than those I would face if I could drive. I often have to pay for parking when normally I would simply have walked somewhere. I have had to pay for taxis/overnight hotel stays to be able to attend private medical appointments because trying to travel on the same day as my appointment was impossible earlier in my illness. (LCAP12)*

For some these costs became prohibitive, leading to knock-on effects in terms of their ability to meet up with friends and family:

> *I've not seen my friends since August 2023 because I can't afford to Uber that far to them. I haven't seen my family since December 2023 because the train tickets would be too expensive with our outgoings. (LCAP03)*

Other costs were associated with lifestyle changes caused by Long COVID. For example, Long COVID can sometimes lead to digestive issues and food intolerances, leading to one participant having to spend extra money on more specialist 'free-from' foods. As an energy-limiting condition Long COVID also meant participants found it harder to cook from scratch and found themselves relying on more expensive ready meals and take-aways or throwing away food they had been unable to cook when their symptoms worsened for a period.

4.4 Financial Strain

The net result of both falling income and increased costs meant almost all our participants found themselves under increasing financial strain:

> *We have a few months until we're through our savings, my sick pay runs out, and we'll have to choose between mortgage or medical treatments to maintain my low quality of life [….] we're a few months from losing everything. (LCAP03)*

Many reported trying to cut back on expenditure on necessities such as food or energy within their household. Multiple participants faced a form of pressure on their housing situation. One participant had had to sell their house due to the impacts of Long COVID on their financial situation, while another was uncertain if they would be able re-mortgage their property when the time came due their reduced household income. Some participants had moved to cheaper rental accommodation or shared accommodation, while others were concerned about the sustainability of affording their current accommodation with a different financial position.

Participants also spoke about the pressure their fall in income placed upon partners, dependents, and family who often played a crucial role in participants' care.[21] One participant recounted in follow-up email, post-interview, how they were concerned their illness made them financially dependent on their partner:

> *I've been financially independent since I was 18 but now I'm dependent on him and it makes me feel anxious. I love him, however I'm aware lots of relationships end and don't want to be trapped economically if things go south. (LCAP03).*

Participants also expressed concerns about the longer-term impacts of their reduced income and inability to work as insurance cover expired, incomes fell and savings were exhausted:

> *Whilst it's less obvious than day to day spending, I am very aware that my longer-term finances have been significantly affected due to my inability to work – my pension contributions are much reduced and due to the fact I cannot work. I am excluded from bonus/executive share schemes at work. These schemes are ones I have previously used for longer term saving. (LCAP12)*

[21] While this did not come up in our interviews, early audiences for this report also flagged how they either had to pay for care or their illness has resulted in friends and family taking on the role of unpaid carers, with subsequent implications for their income.

5. Conclusion

All our participants found their working lives had changed significantly once they developed Long COVID. They found themselves having to adapt their roles, move to part time work or give up work completely, even though all expressed a strong desire to continue working if they could. These changes were not instantaneous, but happened often over months and years, creating an atmosphere of ongoing uncertainty and insecurity. Some participants benefited from employers who were supportive, but all reported a lack of broader understanding from colleagues and management about the chronic and dynamic nature of Long COVID.

Depending on their work and domestic situation our participants were potentially eligible for a range of different benefits, from private income and health insurance policies either accessed through employers or privately held, to government schemes. While some had successfully accessed this support, many faced multiple challenges in doing so, including understanding what benefits they were entitled to, precuring the evidenced required to claim, and navigating bureaucratic and time-consuming application processes and – at times – unhelpful staff.

In addition to often finding their income falling, people with Long COVID also described meeting new and rising costs associated with managing their condition including private healthcare, complementary and alternative medicine, the costs of medical aids such as wheelchairs, and increasing living costs including increased spending on food and transport.

The result was that many of our participants found themselves experiencing significant financial hardship, housing insecurity and concerns about their long-term financial independence.

Many of these impacts are not unexpected, although this research has brought to the fore some additional factors, such as the additional supplementary and alternative treatment costs incurred, which we have not seen discussed extensively in previous work. Arguably more important, however, is hearing these experiences described in participants' own words.

Our interviewees testimonies highlight the personal and emotional as well as financial costs contracting and living with Long COVID[22]. This is reflected in grief over no longer being able to pursue careers they loved and a sense of stigma associated with applying for and receiving benefits. Underlying concerns about the burdens placed on family, friends and dependents—financially, emotionally, and personally—are further exacerbated by fears of an uncertain financial future.

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[22] Compare Fang et al 'I am just a shadow of who I used to be'.