UK COVID-19 INQUIRY

EXHIBIT OS/16

CASE STUDIES PROVIDED BY LONG COVID SOS

Case studies exhibiting the impact of Long Covid on individuals and whether they were aware of public messaging by the government on Long Covid

Case Study 1

Personal Information	O, 59 years old
When did you first fall ill with Covid?	May 24th 2020
When did you become aware that you had Long Covid?	I was a Covid frontline Nurse in the first wave and at the point I went down with covid, 'Long Covid' had not been mooted as a thing. As a result, my ongoing symptoms were often met with scepticism and a degree of 'gaslighting'. By about September 2020 I was classified as a 'long hauler' but there was still no real awareness then of Long Covid and what the trajectory was
What did you know about Long Covid before you found out that you had Long Covid?	I developed Long Covid in real time - in that it was an emerging story alongside my symptoms emerging so I knew nothing at all about it – no one really did.
Did your GP or other healthcare provider know what Long Covid was?	I originally fell under the care of the Infectious Diseases clinic as there was no specific Covid/Long Covid provision. My GP treated each individual symptom as it arose but there was no awareness that this was an emerging picture of something long-term or something that did not follow the norms and trajectories of other viruses. The infectious disease consultant was at a loss to understand what was going on for his patients and told me we were writing the textbooks in real time and the more we could describe what was happening the more insight he could gain. It was, and remains a very scary situation to be in. Whilst recognition is now improved, we are still desperate for robust and urgent research. Rehab and gaining access to services has been a real battle – and I say that as a senior Nurse with many years' experience of the system. LC patients have had to be their own advocates – at a time when many like me have been just struggling to survive and get through each day.

What public messaging had you seen or heard about Long Covid before you fell ill and thereafter?	I had seen nothing before I fell ill with covid and little to none since. It feels like a 'hidden disease'. In some ways I understand how this would have been initially as it was an emerging picture. But even now there seems to be very little public acknowledgement or messaging. I sometimes fell like it is convenient to sweep Long Covid along with myalgic encephalomyelitis (ME) or post-viral fatigue syndrome (PVFS) and to some extent some of the symptoms are similar. But Long Covid is very much its own entity with its own unique set of symptoms and aetiology and it is frustrating that it is not treated as such.
Were you aware of the 'Long Covid' video published by the Department of Health and Social Care in October 2020?	No
What impact did Long Covid have on your health, please specify symptoms, any particular damage e.g. myocarditis etc, and health impairments generally?	I have ongoing cognitive, executive functioning, memory, processing, and sensory issues. It presents like a 'post-concussion syndrome' and I have been told it is probably due to inflammation in my brain. This often effects my ability to self-care, my ability to be around other people, social interactions, to follow conversations etc. I am under a neuro rehab team who have explained how this kind of injury can be exhausting and can then push the whole body into a relapse. I have gone from being a Nursing Sister with a full-on social life to a virtual recluse. I no longer drive. I have balance issues and have had to learn to walk properly again. I struggle to read or process written information. I have ongoing cardiac issues with arrhythmia and pain. I am under the care of a cardiologist and on medication. Initially I was offered ablation, but the inflammation became too widespread within my heart so now that is no longer an option. The arrhythmia can be strong enough to make it hard to catch my breath or can make me lightheaded and dizzy. I have ongoing issues with breathing that sometimes makes me feel like I can't catch my breath and limits physical activity and sometimes makes it hard to speak. My voice is very hoarse at times. I have periods of sleep apnoea. I have pain from a vertebra that shattered because of the inflammation from covid that was in my lungs and chest. I have polyarthralgia that effects all my joints and limits mobility and activity. I have sleep disturbance and am on medication for that. I have PTSD symptoms – partly from being so desperately unwell to the point I had said goodbye to my children and form the sheer level of pain and suffering I have encountered over the past 3 years.

	I have gut disturbances and digestive issues. I am on medication for that. My appetite is labile and my weight yo-yos. I have muscle fatigue that means I tire very quickly which limits my physical activity. My hair goes through periods of falling out in handfuls.
How did Long Covid affect your employment or financial circumstances?	I was previously a Nursing Sister and had previously been a manager in a care home and also a Ward Sister for an acute medical unit in a major teaching hospital. At the time oc Cpvod-19 I was an independent community Nursing Sister and became a Covid Specialist Community Nurse. Since 24 May 2020, I have been unable to work at all. Because I was self-employed I did not receive any sick leave payments. I have had to move out of my home and rent it out to generate some income to survive on. I have taken loans out from friends and am supported by a community charity to cover the basics while I attempt to pay back my debts. I am currently homeless and have been staying at various friends' houses while they go on holiday as a 'house sitter/pet sitter'. Whilst I am truly grateful for this opportunity and friends' generosity the situation is far from conducive to recovery and I have moved 16 times in the past 8 months and am living out of suitcases. I doubt I will ever be able to return to my own home and be able to afford to live there again which has been a source of much grief. I was a lone parent with 4 children and do not have savings to fall back on and as a nurse I have a will have a very basic pension when the time comes. If I am ever well enough to work again I will have to build my client base up again and start again from scratch. Long Covid has devastated and pretty much destroyed every single aspect of my life and my future is worryingly uncertain.
What impact did Long Covid have on your personal life?	I was previously gregarious and outgoing and very much the life and soul. I had a vibrant social life and was surrounded by friends. I struggle to be around anyone for long, conversations literally make my brain hurt. I have lost so much confidence – I often don't quite understand what is being said and my perspective is often skewed which leaves me questioning myself and feeling very vulnerable particularly in a group setting. I was always known as the strong one and the 'healer' in my friendships. To now be perceived as the 'sick one' and for so long has been devastating to my self-esteem. I look very different physically and have aged terribly with Long Covid and that too makes me want to hide away. Simple pleasures like going out for a walk with friends is at times impossible and I can never plan ahead for anything – Long Covid 'crashes' are a constant thing I need to factor in and navigate. Sometimes I will carry through an activity like meeting a friend for lunch knowing full well that I will 'pay

	for it' for the next few days but I can't bear the thought of life just passing me by or friends forgetting me.
How did Long Covid affect you home and family life?	I no longer have a home. I struggle to maintain a sense of strength around my children and worry that they perceive me as 'weak' and feel somehow responsible for me in some way rather than the other way around.
How is your health now – do you continue to suffer health impairment?	My health is as detailed in above. I have ongoing impairments and sitting with the uncertainty of not knowing if any improvement is on the horizon is often overwhelming. My life is unrecognisable to how I lived previously and sometimes is difficult to endure with the impairments and discomforts and daily battles – physical, emotional and financial. I have at times felt suicidal and prayed not to wake up again.

Case study 2

Personal Information	G, 53 years old
When did you first fall ill with Covid?	12 December 2020
When did you become aware that you had Long Covid?	February/March 2021
What did you know about Long Covid before you found out that you had Long Covid?	The suspicion came after hours/days/weeks of hunting the Internet for answers. I knew nothing up until this point, only the testimonials of people with lived experience.
Did your GP or other healthcare provider know what Long Covid was?	I was the first person in the GP practice who was diagnosed with Long Covid. My GP diagnosed, with the information he had available to him. Mainly me and the symptoms I presented post Covid-19 infection and the time frame from my initial infection to that date.
What public messaging had you seen or heard about Long Covid before you fell ill and thereafter?	Zero
Were you aware of the 'Long Covid' video published by the Department of Health and Social Care in October 2020?	I wasn't aware. And I was too ill to view anything or have the cognitive ability to process it.
What impact did Long Covid have on your health, please specify symptoms, any particular damage e.g. myocarditis etc, and health impairments generally?	Generally, I have apart from how I look, have had significant impact on me as a person. I am still under clinical investigation and have a limited life due to the significant impact of Long Covid. I am now just short of 3 years. Impact 1 Cognitive function- process information, causing headaches, and loss of memory on recall.

	2 Shortness of breath - I now have to use an inhaler, I have to work within a very strict bubble of physical ability in order to have daily function. Increased physical activity causes PESE/PEM still under investigation. One day = 2 days recovery. 3 Fatigue- As above significantly managed periods of enforced rest. Before, I was very active. The Fatigue isn't tiredness, it feels cellular, it feels with every pulse that goes through my body my muscles and ability slow down. Sometimes even rest isn't an escape as the cognitive side kicks in and nuero issues present themselves. Fatigue is both physical and cognitive. Body and brain fatigue. 4 Heart flutter- almost from the start of my long covid, ups and downs of heart rate. At times for no reason, sitting still not even moving. Under investigation, still no answers. 5 Migraines- Patches of cluster headaches, noise sensitivity, light and the pain. Diagnosed and medicated. None pre covid. 6 Diarrhoea/GI issues- on and off. Stomach cramps and periodic nausea.
How did Long Covid affect your employment or financial circumstances?	In total 18 months, however to date still having an effect. I returned to work, managed, phased return reduced hours etc. Covid still has an effect on my work as I am under what feels like constant advocacy and pressure from HR to push hard to meet policy guidelines written in a pre-covid time. I work within a very large care provider.
What impact did Long Covid have on your personal life?	There are not enough words in the English language to answer this question. It has had a significant impact on my every day life. I had to be taken to the toilet, as I couldn't walk the 3 to 5 metres on my own. Even getting out of bed, putting my feet on the floor was like fighting lungs full of sand that wouldn't inflate. I had to be fed, because I couldn't feed myself. I was woken up as I slept so long my family thought I had died in my sleep. It has placed significant impact on my family, friends and my loved ones. My wife has a husband, of sorts. It feels like my children lost their Dad. I am still me, but not me.

	I had medical professionals cry in early 2021 as they couldn't do anything for me. But, tell me to rest. This as I left A&E. Long Covid has bled into every aspect of my day and night. Before long covid. I was free, spontaneous. Now I have to say no. No to a 6 year old child who has to see his Dad medicate his way through the day. On impact, there are not enough words. This is lived experience is a horror story. I have been subkect to investigations for over 2.5 years. There has been no cure, no answers, no treatment. That's the impact of Long covid.
How did Long Covid affect you home and family life?	As above. I am a shell of the man I was. Long covid has taken the husband, the dad, the son and the brother from me. As a family, we can't do what normal families do. As a husband, there are very personal that I miss. I can't do with the freedom I had before the things I could do. I was always doing something, for me, us or my neighbours. Now, I say no, sorry I can't. I did once a couple of times in fact. As a result I ended up sat on the pavement short of breath, shortness of breath had kicked in. How did Long covid affect my life? It still does.
How is your health now – do you continue to suffer health impairment?	As per my answers above. I manage now, on mechanisms, techniques and practices I have learnt from peer support groups. My health now? Limited. Affected by Covid-19. Medicated to give function, impaired by shortness of breath, cognitive issues and fatigue.

Case Study 3

Personal Information	H, 53 years old
When did you first fall ill with Covid?	I was coughed at on the tube on 25 Jan 2020, I was ill from beginning of February for 6 weeks with an atypical cough. I asked my GP and she said they were only testing people who had been abroad. I had 3 rounds of antibiotics and steroids (I'm asthmatic) and then felt a bit better but I was not well for 2 weeks then got hit on March 17 with gastrointestinal problems and breathing problems. Then the symptoms increased rapidly, starting with a temperature and a cough. I had a temperature of over 38 for 9 weeks solid.

When did you become aware that you had Long Covid?	I was in constant contact with my GP who said yes it must be Covid, at that time no one was aware of Long Covid. After 9 weeks of fevers and getting more ill not less NHS111 put me in touch with a Covid Hub at Edgware Hospital who said they were seeing quite a few people not getting better. First wavers found each other through social media and the term Long Covid was used mid 2020.
What did you know about Long Covid before you found out that you had Long Covid?	Nothing it didn't exist. I was one of the first wave.
Did your GP or other healthcare provider know what Long Covid was?	No, they learnt at the same time as the patients.
What public messaging had you seen or heard about Long Covid before you fell ill and thereafter?	None at all. It's was supposed to be a 2 week virus and you'd either die or get better.
Were you aware of the 'Long Covid' video published by the Department of Health and Social Care in October 2020?	Yes as I knew the person in it Tom, from our Body Politic Long Covid support group
What impact did Long Covid have on your health, please specify symptoms, any particular damage e.g. myocarditis etc, and health impairments generally?	I am still ill 3.5 years later. I was bed bound for the first 4-6 months and severely ill for the first year. I couldn't walk any distance at all for 18 months and I am still am not back to pre-Covid walking levels. I have a dog and would regularly walk 15,000-20,000 steps a day. Now I use a walking stick and walk 2,000 steps around the house and maybe to the coffee shop on the corner of my road. My heart and chest have been affected badly. I had pericarditis, myocarditis and a pericardial effusion. I am on various heart medications still. For a year I severe chest pain like a stitch in my heart. Had numerous x rays and CT scans to be checked for pulmonary embolism. Now I am on medication that helps although it flares occasionally still. I had palpitations and tachycardia and have had 5 echocardiograms, 2 cardiac MRI and 3 5 day holter monitors and I have frequent noticeable and painful ectopic beats. All somewhat controlled with the heart medications. My heart rate would randomly jump to 130 bpm while sleeping and I would I would often stop breathing at night and wake gasping for air. I had problems controlling my breathing and would have to manually breathe for hours daily and especially the evenings.

	My asthma is worse and I have new medications and take more inhalers. I also have new onset allergies and am on medications for it, and waiting for the allergy clinic. I have had very strong allergic reaction to things where I go bright purple and get a bad headache and sore throat and my asthma gets bad. Reoccurring sore throat, earache and sinus problems. Voice problems where I lose my voice or it gets very weak. I have now got high blood pressure and am on medication for it. I have now got high cholesterol and again on medication for it. I had new onset migraines that lasted for weeks and had to take migraine medication for the first time ever which I still take. I have horrendous constant ringing tinnitus. It gets worse if I've had too much mental stimulation. Also occasional pulsatile tinnitus. Had brain MRI s to check for tumours. My hair fell out in handfuls and it still occasionally starts shedding and get very thin on top. I have PTSD from getting ill in the first wave of a novel virus and never recovering and being told by doctors my symptoms were anxiety. I am on PTSD medication now and having counselling and I am waiting for trauma therapy. I have frequent flashbacks when I hear ambulances from those first few frightening months. I had sleeping problems for 18 months and now I take sleeping medication. I spent a year dreading nighttime as I had to sleep upright for 4 months and would frequently wake gasping for air. Nights were long and scary. I have horrific and violent nightmares now, and my husband has to sometimes wake me as he can hear I'm distressed in my dreams and I have woken myself up shouting and screaming in my sleep. Frequent myclonic jerks during sleep, far more than before covid. Night times are horrible really. I had severe diarrhoea and nausea for months and I still suffer from acid reflux. I am on medications for it. I have problems with my autonomic nervous system and I have small fibre neuropathy and temperature regulation problems. I have had many neurological issues, I had swallowing problems and I frequently choke on food. Still ongoing but less so. I also gulp for air mid sentence and lose my voice.

	I have cognitive problems and cannot drive. My brain/ eye signals are a bit slow and I had a near miss with another car so stopped driving. Last time I drove 10 minutes I came home and slept for 2.5 hours. I used to regularly jump in the car and drive 4 hours down the M4 to see my parents in Wales. I've always been a confident driver. I have quite noticeable tremors so cannot work as a jeweller or illustrator. I have to sometimes hold a glass of water with 2 hands as I'm shaking uncontrollably. Frequent and painful cramps in my legs feet and hands and I had such violent muscle fasciculations in the first year I filmed them. I have short term memory problems. I forget words mid sentence and make up something random. I forget what I'm talking about and just stop. My spelling has become terrible. I have fatigue that is like hitting a wall. I still need a nap everyday to function. I go to bed very early, before my 16 year old. I have balance issues. I am very clumsy and I stagger like I'm drunk when I'm tired. I drop things and trip often. I have fallen downstairs a few times and I sometimes forget how to go downstairs and falter at the top. My hormones have been affected - I am menopausal and do not menstruate but I had very heavy periods in the first 6 months of covid and infrequently for a year. I had to have a scan to rule out cancer. I had reoccurring cold sores in the first year every few weeks. I had reoccurring conjunctivitis for 6 months and reoccurring blepharitis. I had liver problems but they have resolved. I had kidney problems but have now resolved. I have probably forgotten some others, but I have been affected horribly and pretty much every part of my body.
How did Long Covid affect your employment or financial circumstances?	I was made redundant just before Covid but was working prior to that for 25 years as an Archaeological Illustrator. I had just retrained as a Silversmith and was in the process of starting up a jewellery business. I was expecting to be a freelance illustrator and sell my jewellery and a local shop

	was interested. I have not worked since as my tremors and cognitive problems make it impossible.
What impact did Long Covid have on your personal life?	I have lost a lot of friends who didn't understand why I wasn't getting better. My life has become much smaller and I only see 4 friends now who have stuck by me. I can only see a few people at a time otherwise I become overwhelmed. I don't go out much, I can't walk very far and it's painful. I used to go to galleries and exhibitions but I don't any more. I have put on a lot of weight as I used to be so active and now I'm not. I can't walk my dog. I'm a shadow of who I used to be. I've lost my joy and spark and love of life. It's very sad. I don't work but I'm volunteering with Long Covid SOS. Having Long Covid has affected every part of my life. It's unrecognisable from my life pre Covid. My life has altered beyond all recognition. I've lost my independence, my livelihood and rely on my husband and family for everything. I am very bad at retaining information, I was an avid reader and now I read very slowly and forget the plot. I also need recaps on TV shows and films otherwise I can't remember them. I can't keep up with lots of conversations and I have a large family who I do struggle to understand now. I have to take myself off for a nap to get my head clear again.
How did Long Covid affect you home and family life?	I have a fantastic husband who has been my rock. And my child is now a 16 year old who has lost the mother that I used to be, things are not the same for any of us. Both my husband and child have had been though a lot. My child has to have counselling for what they have experienced watching me go through such a devastating transformation in life. We were all afraid I was going to die in those early months. My husband has had to do everything for us all. He had to be the sole breadwinner, cook, clean, look after me, look after our child, take the dog out, do all the shopping etc. he has to drive me to see my family and to hospital appointments. I was completely independent before. I can cook again now but I am not the same as I was before I got Covid. It took a year before I could cook simple meals. I still need a lot of help and I cannot load and unload the washing machine, or carry shopping. Our family is still together but it's been very difficult and I feel awful they have had to go through this. We are all very changed by the experience.
How is your health now – do you continue to suffer health impairment?	Yes. I am better that I was 3 years ago but I am nowhere near back to who I was before Covid. I am on 9 new medications that I didn't take before Covid. They keep my symptoms somewhat at bay. I still have heart and chest problems but these are improving. I have high blood pressure and high cholesterol that I take medication for.

	Allergies have made my asthma worse, again more medication. I have tremors and weakness which means I am unable to resume illustrating or silversmithing. I cannot walk my dog due to pain. I still have Cognitive problems so I am unsafe to drive and I am forgetful and slow, and migraines which I am on medication for. I still have ongoing gastrointestinal problems and my diet is limited.

Case Study 4

Personal information	K, 41 years old
When did you first fall ill with Covid?	19 March 2020
When did you become aware that you had Long Covid?	I first read about other people not getting better on Twitter around 6-7 weeks after first contracting Covid, so around May 2020, although at the time we didn't realise what we were calling Long Covid would be anything as long-term and indefinite as we now consider it to be. I had been told by my boss after a few weeks that he'd heard of some people not better after 8 weeks which seemed an impossibly long time at that point. Now it feels like the blink of an eye.
What did you know about Long Covid before you found out that you had Long Covid?	Nothing – we were all discovering that we weren't getting better collectively and as part of the first wave of Covid, patients were naming the condition at that point.
Did your GP or other healthcare provider know what Long Covid was?	My GP did tell me in May/June 2020 that some people who'd had Covid didn't seem to be recovering quickly.
What public messaging had you seen or heard about Long Covid before you fell ill and thereafter?	I had no idea, I thought it was just going to be a cold because I was 37, went to the gym several times a week and all the messaging was that Covid was nothing to worry about if you were young. It was before the first lockdown so everyone was carefully washing their hands and not wanting to touch anything – I had to go to Oxford for a work course on 16 March 2020 and you couldn't buy hand sanitiser, but I spent all day in a room with people who had flown in from all over the world.
Were you aware of the 'Long Covid' video published by the Department of Health and Social Care in October 2020?	Yes – it felt like huge recognition of what we'd been telling our colleagues, friends and family, that we (people with Long Covid) genuinely were not getting better, that Covid had made us seriously unwell/disabled and they should be careful about protecting themselves from infection.

What impact did Long Covid have on your health, please specify symptoms, any particular damage e.g. myocarditis etc, and health impairments generally?	Huge fatigue, exercise intolerance, orthostatic hypotension, cognitive impairments, memory problems, exertional tachycardia, vestibular dysfunction, vertigo, eustachian tube pain and dysfunction, new pituitary microadenoma causing secondary hypothyroidism, hoarse voice, headaches, dizziness, altered sleep, chest pains, palpitations, breathing difficulties requiring steroid inhaler, impact on liver causing temporary non-alcoholic steatohepatitis.
How did Long Covid affect your employment or financial circumstances?	I work as a Head of Knowledge Management for a professional body. I had only started the job in Dec 2019 so had just passed probation and qualified for company sick pay when I came down with Covid. I kept trying to get back to work from home even while I was sick with acute Covid because I was concerned I would lose my new job. I was

	eventually signed off by my GP for a month at the end of May to try and recover – when I had been trying to work before then it took so much out of me and I knew I wasn't making any sense, I couldn't remember what I was saying in meetings before I got halfway through a sentence, I could barely read emails. I had a big relapse in that month off and got signed off for another month, and then another. By early August my sick pay was exhausted and although I managed to negotiate a bit more, my boss told me to come back to work and just do what I could. I returned in August 2020 working from home but I can't remember anything of the rest of the year. I used annual leave to make the weeks shorter and in 2021 temporarily cut my working hours for 3 months, but I again can not remember anything of work during this period. I found it hard to manage financially – I live alone, have a mortgage and pets to feed – during this period so returned to full-time work in April 2021. Fortunately my boss has been very understanding, and allowed me to continue working from home as well as understanding that tasks take me longer and my memory isn't great. I use workarounds where I can to avoid it looking like I don't remember things about what I do, but it's been incredibly challenging. To keep up with the work I generally work 9 or 10 hour days although I feel like I don't achieve much in that time, and I get frustrated that I can't focus or I can't remember what I need to. I know I miss out on a lot of development and social interactions because I can't go to work, and I am constantly exhausted. I have to give over my whole weekend to resting, as well as cooking a pot of food for the week as I wouldn't be able to manage to cook in the week – even deciding what to eat as well as the energy required to cook would be too much. That means I have essentially eaten the same dinner 6 nights a week for the last few years. Living like this is incredibly draining and stressful and depressing – I don't have the energy for anything enjoyable because I have to save it for work – even though I know I am lucky to have a job and be able to do what I can manage. I don't know how much longer I can keep going like this but what choice do I have?
What impact did Long Covid have on your personal life?	Long Covid has killed my personal life stone dead. I am too fatigued to travel or drive, so I cannot see my family as they all live too far away for me to drive that far safely whereas I used to visit them regularly. Public transport is incredibly stressful and so fatiguing that it is not worth it, and even when I do see my family social interaction is limited because it is overwhelming and exhausting. I used to love going out

	with my camera and taking photos in local parks and in London, I can't do that now. I used to go out and see friends, attend rugby matches, go to the cinema and the gym, I wanted to get into cycling, I can't do any of that now. I have been a bookworm since I could read but I find it hard to focus on a story and remember it these days. I love my garden but don't really have the energy to maintain it and it's hard to see it deteriorating because the flowers really lift me. I have to have my shopping delivered as I couldn't manage to go round the supermarket for a weekly shop and then carry it home or drive home when that tired.
How did Long Covid affect you home and family life?	I live on my own and it is so hard to keep up with washing and cooking, I have to have a cleaner visit because I just can't manage that. I struggle to keep up with the garden too, and I have pets and it's hard to explain to the vets that I can't always easily go out and pick up a prescription. I worry that if I deteriorate further I won't be able to look after them. I don't see my family often anymore, I can't drive far enough to visit them and they feel it's too far to collect me for a visit and then bring me home – either a 4 or 6 hour round trip twice. It's also really hard to talk to them about Long Covid, they find it hard to accept that I'm disabled and keep telling me I should 'try and get better' for something they want to do, not accepting that if it was just a case of trying I would be better by now. It is hugely isolating and dispiriting to hear that, or for them to blank me when I try to talk about the impact Long Covid is having on my quality of life. After more than 3 and a half years it's still my responsibility to try and manage their emotions about my disability as well as my own, and it is another challenge on top of the physical symptoms. I feel very alone and am incredibly grateful that I know other people with Long Covid through an online forum as well as on a research study PPI group, as I at least can talk about the challenges to people who are going through similar challenges.
How is your health now – do you continue to suffer health impairment?	Yes, Long Covid still dictates my life. I get post-exertional symptom exacerbation and fatigue, have difficulty in pretty much everything I do including work, and I can definitely do less e.g. around the house than I could in 2020 or 2021. I definitely feel like I am deteriorating and hugely exhausted from trying to keep going at work. I don't think I could change jobs because no-one would employ me. I still can't drive far, have vestibular processing issues but if I try to do vestibular rehab then I just start losing my balance and falling over. If I'm stressed even if I know that I'm not concerned – talking to important people at work or having

	to walk a little faster than my new slow pace, my tachycardia makes me feel really unwell – my HR has been 137 in a work meeting when I've been sitting at home, and 160 when walking slightly faster than usual for 3 minutes, both in the last few months. I am struggling to manage my energy and do the bare minimum to keep eating and myself clean. If I have to do something outside my energy envelope, I crash an indeterminate amount of time later – anything from hours to a few days, even if I try to mitigate the exertion by resting. I end up taking a Covid test if I've had to overexert by going out, because the symptoms of my initial infection – sore throat, burning lungs, blocked nose, feeling flu-ey – return and I am not sure if I've been reinfected or it's a relapse. I am losing hope of ever getting better and when I've really struggled I have considered signing up for Dignitas because I feel trapped in an impossible Catch-22 life…

Case Study 5

Personal information	S, 54 years old
When did you first fall ill with Covid?	18th January 2021
When did you become aware that you had Long Covid?	March 2021
What did you know about Long Covid *before* you found out that you had Long Covid?	I knew very little about Long Covid, but as I already had asthma and fibromyalgia, a clinical friend had told me that Long Covid could make my existing conditions worse. That was all I knew.
Did your GP or other healthcare provider know what Long Covid was?	The practice nurse knew what Long Covid was and referred me to the Long Covid Clinic in Derbyshire in March 2021
What public messaging had you seen or heard about Long Covid before you fell ill and thereafter?	I had seen no public messaging before I contracted Covid in Jan 2021, I have seen none since in my geographical area.
Were you aware of the 'Long Covid' video published by the Department of Health and Social Care in October 2020?	No…?! Where was it published?
What impact did Long Covid have on your health, please specify symptoms, any particular damage	Long Covid has broken me… I have CFS and PEM

e.g. myocarditis etc, and health impairments generally?	I had two partially collapsed lungs for the first 18 months. I have hearing loss and tinnitus, and now have to wear two hearing aids. I have cognitive impairment which has been likened to minor brain damage. I have autonomic disfunction which means I cannot control my body temperature, hardly sweat at all, I have an increase in IBS symptoms, I am mildly incontinent and have been diagnosed with POTS. I have Mast Cell Activation Syndrome which means I am constantly itchy, have low blood pressure wheezy and light headed. I have developed high inflammation markers in my bloody and have suspected Sjogren's Disease - which has left me with painful joints, itchy skin, swollen glands, a horribly dry mouth, and I am unable to cry... I also have a damaged voice box, which has left me unable to speak for long periods of time. I am also unable to sing because of this; I used to write songs and sing a lot to relax, now I can't.
How did Long Covid affect your employment or financial circumstances?	I had 11 months off sick. I tried to go back in December 2021 and was given an 8 week phased return. In January 2022 when the 8 weeks was up, I was expected to be full time and go on campus 2/3 days a week - I tried, but I wasn't well enough. My team was then restructured and my role made even more senior. I was asked whether I thought I was well enough to take on a more senior role - I wasn't well enough, so I was made redundant, and thankfully was awarded ill health retirement by the Teacher's Pension scheme - but I felt pushed out. Thankfully my wife has a well paid job, as my pension is only half of what I earned. I LOVED my job.
What impact did Long Covid have on your personal life?	Long Covid has affected every aspect of my life. I have little energy to drive my car or travel to places, so most days I stay at home. I have terrible mobility issues now from pain, stiffness and dizziness. I use walking aids, I have had to have handles fitted around the house and garden, and we have had our toilets raised to make them easier for me to use. When my wife is away I often struggle to cook, get dressed and shower and rely on my friends for shopping, gardening and walking the dog regularly. Once when my wife was unwell, I stayed in the same clothes for three days as I didn't feel well enough or have the energy to change. When I try to do things, I always do too much, which can knock me back - sometimes for days.

	I now have to avoid emotional situations as much as I can because I can't cry, this is probably the hardest symptom to deal with - I have started having panic attacks instead of crying. Also as an academic, I have been used to reading, writing and critiquing knowledge, information and evidence at a fairly high level - now I do not the have the cognitive ability to think through complex theory or presentations. On a good day I can still be articulate and write fluently, but on a poor day I miss words out of sentences when I'm writing, and words on the page become too jumbled to read, I also struggle to find words and begin to stutter. Instead of reading I now listen to audio books and use some AI tech to help me put my thoughts down on a page.
How did Long Covid affect you home and family life?	The impact of such dramatic changes to myself and wellbeing have considerably impacted my mental health. Good friends have stuck with me, but it has been tough for us all. I now spend my life waiting for appointments to come through and hope they are online so that I do not have to find someone to take me to the hospital or clinic. My wife has been amazing, she is now my wife and my carer - something I really struggle with, but she is amazing and take it all in her stride.
How is your health now – do you continue to suffer health impairment ?	I had Covid for a second time in July 2022, and since then I have become more unwell. I have been told that my CFS and PEM may improve, but other conditions such as hearing, tinnitus, damaged voice box, Sjogrens, MCAS and POTS probably wont get better. I despair at the lack of public health messaging around Covid. The fewer people catch Covid, the fewer will develop Long Covid.

Additional case studies exhibiting the range of problems people with Long Covid experience

Case	C-19 Infection	Harm and Impact
R	March 2020 [no testing available]	Original symptoms: I couldn't talk at all due to breathing problems I have been bedbound, unable to work properly, to support myself, or to have anything resembling a productive life. I am reliant on two carers.

		The impact of Long COVID on my life is quite literally that it has destroyed my life. With no exaggeration, I have almost no life left, and before I contracted COVID I was completely healthy and happy with no underlying health conditions, and I was under 30. *I am no longer able to work more than a few hours a week due to fatigue, PEM and cognitive dysfunction. I am no longer able to leave the house without someone pushing me in a wheelchair, and even then only for very short amounts of time, due to the same symptoms.* July 2023: *I am actually unable to leave the house or work at all now*
M	March 2020 [no testing available but positive anti-body]	Original symptoms: For the first two months after covid I could not walk to the bathroom due to intense chest pain and breathlessness. I was confused and disorientated. I propped up in bed gasping for air and had fully accepted I may die and that I was unlikely to get any medical help. I very slowly returned to mobility over the next year but from March 2020 until December 2020 I was completely reliant on my husband to take care of all my basic needs. *I was unable to walk more than fifteen meters, unable to empty a dishwasher or shower without intense chest pains, breathlessness and dizziness. The slightest effort wore me out. Improvement was painfully slow. I stopped having intense fatigue about November and my mobility improved but my breathing was still very laboured.*

Y	March 2020 [no testing available]	Original symptoms: Started to have fever, diarrhoea and constant headache, vomiting, fatigue. March 22nd 2020 lost smell and taste and coughing. March 26th 2020 I thought I had taken my last breath collapsed on the bed. Short of breath and chest pains, Paramedics called next morning who confirmed suspected Covid19. I was not taken to hospital. *Signed off work until March 2021. My husband and grown children are my carers. Throughout all of this I have been made to feel belittled by some, not believed by some*, I have had to get my local MP involved after a few failed attempts to have my referral picked up at a long covid clinic. It took seven months from referral and eighteen months from beginning of my illness. I am not the same person pre covid. *"No longer able to work due to relapses, now on benefits. House chores, baking and cooking puts me back into relapse. I have to pace very carefully, some days still bedbound, exhausted short of breath and chest pains I have medical oxygen. I cannot cope very well in crowds as I struggle to talk loud."*

M	March 2020 [no testing available]	My first symptoms were headaches and extreme fatigue - too tired to cook for myself. I started to look pale. I was sweating, shivering and had a loss of appetite. I lost 1 stone over 2 months. Vivid nightmares. The following week is when I noticed differences in my breathing. I had a tight chest and it felt like I just couldn't get oxygen into my lungs. 1-2 months in I noticed issues with my memory I would forget what I was talking about mid conversation, mood swings, depression (I would wake up crying and feeling thoughts of hopelessness. Insomnia for 6 weeks starting approx 3-4 weeks after infection where I would sleep approximately 1-2 hours then could not get back to sleep (I have never encountered this before in my life) The fatigue was crushing where it was a struggle to go out for a 10 minute walk once a day without feeling intense chest pressure, heart racing and feeling irregular off set beat then needing a nap in the afternoon and resting the rest of the day. Painful regular headaches. When I would lie down I could feel my heart pumping in my chest like it was bigger and more painfully beating in my chest. I called 111 who then told me to call 999 second week in, paramedics took me into hospital. I was examined and told that I likely had Covid 19 but had no symptoms which were treatable other then insomnia which they offered antihistamine tablets. For abdominal issues on 111s advice I revisited A&E and was prescribed antibiotics. I had 3 extended courses of this. For stomach issues I was prescribed omeprazole. In 2020 I visited A&E multiple times. 5 times was advised by 111. First time I was told by a Dr they only had oxygen for covid patients so I needed to go home. Two times I went for chest pain and I was examined and told some people were suffering what i had but another dr told me I had anxiety. I told the dr I needed stronger medication and was given co-dydramol and recommended to take Gaviscon for stomach.
J	April 2020 [no testing available]	Original symptoms: strange migraine like headache, flu-like symptoms, pains in my body, extreme fatigue and a feeling of constriction around my rib cage. May 2020, I did some strenuous gardening and experienced what I now know is Post Exertional Malaise, extreme crashes that forced me to rest for hours or days afterwards. The autumn and winter of 2020, my energy

		levels stayed extremely low and I slept 12 hours a day, and I was unable to do basic domestic activities. I also experienced extreme crashes in my mood, corresponding with the physical relapses. I started experiencing persistent pain and discomfort in my legs. Two years later has not recovered. *Required to step down from job having been on part time furlough due to symptoms*