



Feedback from Action Group members to provisions funded by the £3 million Long Covid service to each NHS board for 2022-23 (To Feb 2023)

Dated 19/02/2023

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Introduction

This report details written and anonymised feedback by NHS board from Long Covid Scotland's members with regards to service provisions, availability and awareness of The Long Covid service across Scottish NHS boards.

This followed the funding allocation of the £10 million long COVID support fund for addressing long COVID and specifically from the initial £3 million available from the Scottish Governments £10m long COVID Support Fund over the financial year 2022-23 to NHS Boards.

This feedback survey evidences that people with Long Covid are unable to access clinical pathways. They also experience issues with self-referrals, getting treatment, inequalities in care and coding.

Lack of transparency and accountability regarding service planning, implementation of change and issues with non-multi-disciplinary approaches are detailed.

Issues with lived experience not linking with networks and non-delivery are also identified.

1. NHS Ayrshire and Arran, £187,554

- Development of a long COVID multidisciplinary rehabilitation pathway delivering a single point of access for assessment and co-ordinated support from services including physiotherapy, occupational therapy, and psychology, depending on what is most appropriate for a person's needs.
- Liaison with primary care, third sector community support services and where required, onward referral to specialist clinical pathways via normal routes and triage processes.
- Support is currently being provided to people who require this due to long COVID via services already established in the community depending on their symptoms. For example, this may include primary care services, secondary referral to specialist services e.g., respiratory or cardiology pathways, or referral to intermediate care or rehabilitation services. Staff in these services have received specialist training in the management of long COVID, and there is a small cohort of staff supporting people deemed at most need by their general practitioners on a case-by-case basis, dependent on availability of staff.
- Support is also being provided to NHS staff who are experiencing symptoms of long COVID. This is primarily provided in occupational health by a specialist physiotherapist, using a long-term conditions rehabilitation approach.

Comments from patients within this health board

- 'I accessed rehab in late 2020. Can still access if required but discharged from clinic in December 22. Have had referrals made to other specialists via GP. Have had input from community OT, Physio and SW in 2020/21. I'm NHS staff, so have received support from Occupational Health Long covid clinic. I knew what I'd likely benefit from so knew what to ask to be referred to.'
- 'I am in South Ayrshire. As far as I am aware there is nothing at all re help for long covid. I do have an appointment with my GP tomorrow. Should I show them this and ask if they are aware of anything? I have a good hunch what the answer will be!'
- 'Was unaware of a LC clinic. GP has told me there is no clinic in our area. Was referred for MRI & CT brain scan, chest X-ray and heart monitoring separately.'
- 'I'm an NHS nurse, work for AAHB. Their support is excellent. I have full support from OH, HR, LCPT and staff care.'
- 'I have just phoned my medical practice where the receptionist had not heard about this. After going to find out about pathway she returned and asked if I

was an NHS worker and because I'm not, I was told this service is unavailable. She asked where I'd got my information, so upon being told she said, 'So it's in social media'. She went away to ask some more questions and returned to give me an appointment in February to discuss it with a practice GP. I'm totally gobsmacked! It should be available to all and as patients we should not have to push for treatment.'

- 'I have now had a phone call with my GP. She is unaware of this clinic and is now going to find out about it. I handed over the information to her. She was able to say there is a LC clinic for NHS workers. The system is so unfair. I have been infected at work and should be entitled to the same treatment as an NHS worker.'
- 'I've not heard of any of this, and my GP believes there is no LC clinics available in North Ayrshire. I will screen shot this and contact my GP tomorrow.'

Most recent comment Tuesday 14th February 2023

2. NHS Borders, £50,727

- Development of clear and easy to access pathways for those requiring support for long COVID. These pathways will be developed by an advanced practice occupational therapist based in primary care alongside clinicians from other specialties.
- Support is currently being provided for those with long COVID through existing services in line with presenting symptoms. This may mean support from GP, cardiology, respiratory, physiotherapy, occupational therapy or psychology services as appropriate.

Comments from patients within this health board

- 'Not heard anything about a pathway.'
- 'Have had ongoing respiratory support but nothing else...no consideration of other symptoms. GP acknowledges long covid but says she can't help.'
- 'I've had no offer of anything except for the basic bloods and chest x-rays (twice). Though to be honest I've given up asking for help - we don't even have a proper GP practice now, it's run by the Health Board and staffed by locums.'

Most recent comment Wednesday 1st February 2023

3. NHS Dumfries and Galloway, £79,426

- Establishment of a small team of experts to lead on the long COVID Rehabilitation Service development. This includes a Lead GP, AHP, Psychologist and Public Health Practitioner.
- Support is currently being provided for people with long COVID by services which were established for people suffering from ME/CFS/Fibromyalgia. GPs can refer to psychology, AHPs and, if necessary, specialist secondary care services. In due course the Board intend to unify these services into a more bespoke, streamlined service.

Comments from patients within this health board

- 'This is what they have been saying in D&G since 2021. I have letters from 2021 and 2022 stating the same as we see here. I sent a FOI request after these letters and was told that the money had not yet been utilised but that the first appointment (a GP with special interest) would be starting Feb 2022. I have tried to track this GP down to try get an early appointment but neither the hospital nor my GP have been unable to find out how to refer. I am sick of being sent to these specialist services, discharged to my GP and then returned to the specialist services. As far as I have been made aware the specialist ME/ Fibromyalgia service was an A4 sheet stating what ME and Fibro are. Don't believe they can employ a specialist GP, AHP, psychologist (why?) and public health practitioner for £80k a year. As for mental health services I was 18 months from GP to screening appointment and not heard anything in the 6 weeks since. They refused patient participation in the steering group and have done nothing for 2 years.'
- Image of text that says 'steering group to coordinate all groups working on Long Covid, ensure services are aligned with current provision of Chronic Fatigue ME/ Fibromyalgia/ Chronic Pain services and to agree the clinical leads that will progress the work. It is hoped that further information on the progress of the work around Long COVID will be available in the new year.'
- Image of text that says, 'enquiries on your behalf and have been advised by our Medical Director that NHS Dumfries and Galloway are working to establish a Long Covid service, which will be in conjunction with the Chronic Fatigue/ Fatigue/Fibromyalgia clinic comprising of Mental Health, Allied Health Professionals, Public Health and Specialist GP support.'
- Image of a letter dates 28.12.22 that says 'Dumfries and Galloway NHS Board Executive's Office Freedom of Information, NHS Dumfries Galloway 2022. Thank you for your email, dated 7th December 2022, where you requested information through the FOI (Scotland) Act 2002. Please find information below: The Scottish Government funding to recruit to Long Covid posts will not be utilised until early 2023. The Board have recruited a one session GPwSI in Long Covid starting in February looking at developing

and support our Long Covid pathway. Recruitment to other posts is still underway.

'My MSP Oliver Mundell is handling a complaint against them for me now as they will not listen to me.'

- 'My partner has received no support from services established for ME/CFS. Long covid for 15 months and it hasn't even been suggested. It's taken this long to get a referral to neurology and a lung function test. Can't get a referral to rheumatology as in the doctors own words 'I know they will just throw it back and refuse'. Other than that, just numerous rounds of blood tests and an ECG. I have however seen job positions advertised lately which fit the description of this service they are supposedly setting up. I'd love to know why it's taken so long. We are 3 years down the line now!'

Most recent comment Tuesday 24th January 2023

4. NHS Fife, £178,051

- Development of a long COVID rehabilitation pathway, delivering a point of access for assessment and co-ordinated support from services including nursing, physiotherapy, occupational therapy, and others depending on what is most appropriate for a person's needs.
- Support is currently being provided to people who require this due to long COVID via services already established in the community depending on their symptoms. For example, this may include community rehabilitation teams, chronic fatigue service, pulmonary rehabilitation and other services.

Comments from patients within this health board

- 'Sorry can I ask how you get referred to these clinics, I have had long covid for over a year and my GP just says it's long covid here is another course of steroids that don't work. Any help would be appreciated.'
- 'As far as I'm aware everything is through GP. If they are not aware of services, might be worth sending them this info? '
- 'I'm in Fife and know nothing of any of these. I haven't spoken to my GP about LC symptoms in about a year.'
- 'I was ill 2020, and I spoke to my GP frequently then and into 2021. I had needs to get referred or try to get things like Famotidine off them but once I either

couldn't get anywhere with them for some of the requests (for pills not referral) I gave up.'

- 'I will again try and make an appointment with my GP and give him the information. Maybe he is unaware, I do still need to see someone. I am 45 and can't walk up a flight of stairs without needing to rest. That's not right and a year on I would have hoped for some improvement.'
- 'I'm a newbie and in Fife. I've been ill from last September. One GP gave me details for the website Your Covid Recovery and a phone number for a Covid helpline. I'm not aware of any rehabilitation pathway and my GP has referred me to respiratory only and there is a 20-week wait. I brought up POTS and lean test with GP and possible referral to cardio but have not been referred. So, I'm not aware of this service, nor used it and I believe GP is unaware as they have said nothing else available to me. I have queried going private and made GP aware of my appointment with a private clinic.'
- 'I'm in Fife and I have heard about none of this. The chronic fatigue service for which I've been waiting for a phone call for 2 years now just cancelled on me without explanation. Community rehab teams? Physiotherapy? Occupational therapy? Yeah, right. Only actual treatment I've had is privately.'
- 'I've had long covid for 18months. Been given standard chest X-ray and 24 hr ECG - "normal " - not referred anywhere by GP. I'm in Fife. Have paid to go to a private clinic.'
- **Most recent comment Monday 30th January 2023**

5. NHS Forth Valley, £142,020

- Development of a screening service for people referred with long COVID and recruitment of an Allied Health Professional long COVID Coordinator, a Clinical Associate in applied Psychology, a full-time Respiratory Physiotherapist and a parttime Psychologist.
- The screening sessions will provide screening and signposting as well as offering supported self-management groups.
- The long COVID Coordinator will be responsible for the mapping of services and supporting healthcare professionals' understanding of referral pathways available to support patients with long COVID. The Co-ordinator will support the development of local networks, and the organisation and delivery of training, to

ensure that guidance, tools and pathways are shared throughout General practice, primary and secondary care.

- A long COVID pathway is already in place to support referrers in decision making when people present with long COVID symptoms. There is access to supported self- management resources and referral to specialist services based on people's specific and individual needs.

Comments from patients within this health board

- 'I had no idea this was available, and it would appear my GP is also unaware of it.'
- 'I didn't know any of this, but I am going in for tests for my breathing on Thursday so maybe I'll meet the respiratory physio.'
- 'I was not aware of this, and it's not been mentioned by any GP I've seen in the last 18 months; can't say if they're using it now or not. Was pointed to a website initially, and all of my referrals except to neurology have been turned down (immunology, gastro).'
- 'Just phoned doctors they have no clue about this and never heard of it. Doc will get back to me about this 33 months later been ill.'
- 'NHS Falkirk doctor has not a clue. He keeps saying I just don't know. Long Covid since April 2020, 88 weeks on a Respiratory appointment, absolutely no support and still suffering badly. '

Most recent comment Tuesday 24th January 2023

6. NHS Grampian, £254,847

- Development of a long COVID rehabilitation pathway embedded within existing services, including supported self-management, specialist advice for patients and other professionals, onward referral to appropriate services for investigation or treatment, and may include a single point of access for assessment and co-ordinated support, depending on what is most appropriate for a person's needs.
- Identifying and responding to training needs of the wider workforce in health and care in relation to managing long COVID.

- Support is currently being provided to people who require support due to long COVID via existing services in secondary care, primary care and in the community depending on their symptoms and needs. For example, this may include General practice, occupational therapy, physiotherapy, psychology or specialist services.

Comments from patients within this health board

- ‘Wow wasn’t aware of this in Grampian- I have been offered no onward referral for investigation or treatment and would be interested to understand more about the rehab pathway - am assuming this isn’t in place yet- unless others in Grampian have seen something?’
- ‘No dedicated services available as yet in Grampian area. I believe they are starting recruitment. I’ve had no dedicated Long Covid support despite suffering since March 2020. Private diagnosis March 2022 by neurologist in Glasgow. Holter test provided after hospitalisation.’
- ‘From NHS Grampian, I am on the LC Patient steering group with them: Work has been continuing while setting up the new governance structure. Job vacancies for the new Long COVID Clinical Lead and Long COVID Practitioners will be advertised in the new year, along with the launch of the NHS Grampian Long COVID Professional Network.’
- ‘Work from all of the engagement work done to date will be used to inform pathways going forward.’
- ‘I’m involved and have been for over a year in the work to develop a LC service. Nothing up and running as yet. However, good consultation and involvement with Lived experience.’
- ‘I live in Aberdeen City and there is no support for long covid patients at all. No referrals to specialists. The only thing was seeing a respiratory specialist after 5 months. No access to physiotherapy or specialists. My GP does see me but they say there is nothing they can do for my symptoms. No referral or any help for cardio, neuro, nor speech therapy. They have told me to find the Facebook support group and to "get on with it".’
- ‘Zero available. Even less for children and teens.’

Most recent comment Monday 23rd January 2023

7. NHS Greater Glasgow and Clyde, £595,169

- Development of a long COVID rehabilitation pathway, implementing a single point of access for assessment and co-ordinated support. This service model is focussed on Occupational Therapists delivering specialist assessment to those presenting with the common symptoms of long COVID.
- This service will be a primary care service, accessed via referral from GPs and secondary care. As such, it will liaise closely with primary care and community health and locality services referring to specialist services where required.
- Interventions provided will include virtual and telephone assessment, signposting to online and digital resources and support to utilise these, as well as virtual and face to face group sessions and where required individual virtual or face to face appointments.
- Support is currently being provided to people with long COVID via services already established in the community, depending on their symptoms. For example, this may include General practice, primary care services, rehabilitation services, the Centre for Integrative Care and specialist clinical services such as cardiology and respiratory medicine.
- The Board has a dedicated resource to support staff with long COVID to remain in or return to work.

Comments from patients within this health board

- 'I'm in this health board and coded for long Covid but presume the pathway isn't ready yet. My GP last year mentioned a meeting to discuss clinic development.'
- 'My GP made a referral to Respiratory clinic in June 22. Still waiting for an appointment!'
- 'I waited over a year for this. I'm in this health board, and honestly don't see what I had hoped for in the single access of care, seems it will just be different people asking you to cough or breathe down the phone. At the moment in Greenock, by being part of a "peer-to-peer led long covid support group" I know that doctors are actually sending people to us, which is good, but a lot turn up expecting some miracle cure rather than support from others going through the same, the disappointment they show is heart breaking. Through the group I have also witnessed people coming to the group thinking they can help, and we've watched their jaws hit the floor when they realize just what LC does to us. So, from the above I don't see anything that gives me hope.'

- 'Blame LC I forgot to put this, when I did eventually see respiratory consultant. I explained to her in detail about the cough I have emphasizing that it comes on in cycles I can be completely clear of it for weeks then it starts building up again. Now I've been on ramipril to help protect my kidneys for years started on them at two years pre-covid. But she started insisting it was the tablets that cause my cough sarcastically said how clever these tablets were giving me a break from the cough now and then, must have learnt it through COVID as they didn't know how to do it before then. That was ignored she just didn't want to even say the words Long COVID never mind admit it existed. She took more interest in the jewellery I was wearing than anything else.'
- 'My GP hasn't referred me to anything!! I will be nearly 3 years down line. All referrals to respiratory, chest X-rays and bloods all normal!! So, GP doesn't seem worried. Had to finally pay to see a private clinic which diagnosed MCAS and POTS as well as long Covid. Are these pathways only for self-management? I was lucky enough to get a referral to a long Covid service through work (NHS), again self-management but it's just not enough.'
- 'I have had and in the process to multiple specialists via my GP and also a physio referred me to the Centre of Integrated Care which I am still with. I have been discharged from the pain clinic until I get an outcome from neurology, so I may go back.'
- 'I was told to contact Chest, Heart and Stroke Scotland for advice!! After 18 months eventually gave a neuro referral. Have just received the appt after 7 months. Have also received a letter from the post hospitalisation Covid Mental health and wellbeing service situated in Leverndale. Filled out a questionnaire but heard nothing back.'
- 'I was advised to contact CHSS for support. When I approached my MSP he wrote to NHSGGC and I got a letter back saying that GPs can refer to a range of services blah blah. My GP is unaware of a referral pathway.'
- 'My GP doesn't know of any LC services in Glasgow. He has referred me to respiratory and cardiology and I did a self-referral to physio but ended up going to private physio due to wait time. My problem is getting my results which I have to continually chase to be told everything is normal with lung X-Ray, lung CT scan with dye and breathing tests but yet I've still got an appointment for respiratory clinic in July! Been chasing 24hr heart trace results since 2nd November where the nurse commented on how breathless I was. The physio thinks I have vascular problems but my GP hasn't acted on it. I feel as though he's as useful as a chocolate frying pan. Going to see a private clinic in 2 weeks as I feel (it's) my only hope at present.'
- 'Thanks for this. I've to take a pen drive into my GP and they will put my medical records on it. I'll need to ask them if that includes the results that the hospitals

put on the portal since my GP seems to have an issue in looking at said portal for any results. It drives me absolutely crazy. How have you been feeling since your visit to (a private clinic?)

- 'That's great that you are seeing improvements, that's really encouraging. The being able to stand for longer would be great as that's one of my issues too. Thanks for this, I'm literally counting down the days now!'
- 'I am area 7. Covid positive Dec 2021. Ongoing fatigue, breathlessness & GP referred me for chest X-ray & did some blood tests at the practice - these were normal. Kept contact monthly with GP by phone as issued with 4 weekly sickline. No other services offered. Was told about a NHS long Covid rehab programme run by the Nuffield and was under the impression my GP had added me to the waiting list. Ongoing symptoms, still off work and enquired about update for Nuffield in Aug 2022 to be told no I wasn't on it as it was full and list was closed at this time. Contacted Nuffield direct to self-refer myself and the list reopened Sept 2022 - still awaiting contact from them. GP seems uninterested in all things Covid related despite my ongoing symptoms fatigue, breathlessness etc as well as a flare up of eczema since Covid & a recent diagnosis of Lichen Sclerosus which consultant told me is due to autoimmune response related to Covid. I am now being issued with an 8-week sick line. I am not getting any pay since July 2022 but get a percentage of my pay via a works income protection policy. I have monthly contact with a Physiotherapist by phone related to this policy and medical assessments. Asked my GP to repeat my bloods in December 2022 - he refused. Asked if there was anyone else, he could refer me to via him or using my private medical insurance i.e., Respiratory but he said no, see how you are after the Nuffield. I am a nurse no longer frontline/NHS employed and feel beyond frustrated.'
- 'Glasgow, no mention from GP of anything like this. Week beginning 6 Feb saw comms via Greater Glasgow and Clyde Health and Social Care Partnership (NHS and council) re planning and a focus group for this new long covid service.'

Most recent comment Sunday 11th February 2023

8. NHS Highland, £119,641

- Development of a multi-disciplinary complex review group to help signpost and coordinate care for those patients who are severely impacted by long COVID and struggling to recover with rehab.
- The Board already has an operational long COVID pathway, including occupational therapy and physiotherapy staffing to support assessment, goal

setting, rehabilitation and coordination for people with long COVID. The pathway will signpost to self- management resources as a first option and can be stepped up to supported self- management including one to one or group support.

- Close working with third sector colleagues, 'Let's Get on with it Together', in self- management resources, groups and peer support. The team is a board wide virtual team offering remote support by telephone or NHS Near Me (video appointments). The team will be working closely with local services across the wide geographical board area to enhance local support.

Comments from patients within this health board

- 'I'm under the NHS Highland Long Covid service. Only had phone calls. I feel like they want to be helpful but don't know what they're doing. Most of it seems to be done by the OT. There is also a respiratory consultant and psychologist involved but the OT seems to struggle to get hold of the psychologist. When I asked about specific exercises for running out of air talking (previously had respiratory physio for breathing pattern disorder) I was told to lie on my bed and focus on my breathing a few times a day. My normal breathing is fine is specifically with talking that is the issue. I am feeding them information and research papers which I feel I shouldn't have to do.'
- 'Everyone we mention long COVID to denies it and especially Raigmore doctors don't believe in it. Agree with comment above, have to feed and show the info and papers published. They only agree when it means they don't need to be involved. Not interested in helping with recovery and definitely we were not signposted to that service.'
- 'I got Covid 19 in April 2020. There wasn't any covid clinics or even recognition of long covid in the early days, ad you probably know. My GP told me that Long Covid isn't officially a recognised condition and has pointed me in the direction of ME/CFS & Fibromyalgia services. I was referred to a respiratory consultant but was not seen. A letter was sent saying because I wasn't hospitalised or a positive test (tests weren't available to me back then, 2 doctors diagnosed me) then they couldn't see me. I had physio but because I was in so much pain in the shoulders and arms and I couldn't walk without severe Fatigue and breathlessness I was eventually discharged- I was diagnosed with Fibromyalgia by GP. I received respiratory physio- this was helpful a breathing pattern disorder was diagnosed. I was given LGOWIT booklet and I completed it. It was OK, it was easily set out and easy to follow but I feel a lot of information is lacking especially towards Long covid. I was referred to speech therapy via an ENT as my voice was weak and I couldn't hold a conversation for long, this was a HUGE help. I have my voice back. Referred to a Pain Clinic and this has been a massive help, lots of things like pacing, concentrating on getting sleep, just

understanding and talking, feeling listened to has been helpful. I still feel it may be helpful to get help from OT (this has never been offered to me or even mentioned by anyone)- I still can't get in and out of a bath yet, can't cook a meal. I find brain fog is bad and I would love if a specialist could enlighten us on this, sleep alone is not the answer. I would love our hormones to be checked out too.'

Most recent comment Tuesday 24th January 2023

9. NHS Lanarkshire, £320,007

- Delivery of a single access point to a long COVID rehabilitation pathway, supported by a team of occupational therapy, psychology, physiotherapy, dietetics and speech & language therapy. The team can assess and help with physical, mental or social difficulties people may have that are related to long COVID.
- The funding made available through the long COVID Support Fund is contributing towards paying for the multi-disciplinary staff supporting the pathway.
- It will support the implementation of a digital, app-based tool that allows people with long COVID to measure and monitor their symptoms. This information supports the assessment, intervention and evaluation of their care.

Comments from patients within this health board

- 'I'm in Cambuslang, caught covid June 2021. Haven't heard anything about a single access point or been referred to any rehab support by GP. I have had several tests done - lung function (diagnosed with asthma) endoscopy (diagnosed with hernia) home ECG for 2 weeks and eye tests. I've ended up going private in Dundee and a psychologist through my work. Sometimes I go through Lanarkshire for hospital appointments and sometimes I end up in Glasgow. There doesn't seem to be any joined up thinking. Feels like I'm constantly going round in circles but getting nowhere fast'.
- 'I am NHS Lanarkshire. I found out about the covid rehab team through this group, GP had never heard about them. Took umpteen calls to GP before referral was actually submitted. Been seen by physio, had respiratory tests and waiting to see psychology and join the next peer support group.'

Most recent comment Monday 23rd January 2023

10. NHS Lothian, £372,215

- Staged scale-up of the long COVID supported Self-Management Pathway including the digital self-management tool and Chest, Heart & Stroke Scotland advice line.
- Learning from each phase of the pathway will inform the next stage to implement the pathway across NHS Lothian and its partnership areas of East Lothian, West Lothian, Midlothian, and the City of Edinburgh.
- The application of existing data including how many people have received a clinical intervention and the routes taken to access these services, to inform the development of the Lothian model for long COVID services.
- At present, existing NHS Lothian and associated Health and Social Care Partnership services are providing clinical support for people who need intervention to help them manage their symptoms. People with long COVID have access to a wide range of services including respiratory, neurology, rheumatology and musculo-skeletal teams, amongst others.
- In addition, a trial group of GP Practices across Lothian can refer through to the 'Tailored Talks' digital self-management platform, providing access to tailored health information to help them to manage their symptoms and a 12-week programme of support from Chest, Heart & Stroke Scotland's advice line.

Comments from patients within this health board

- 'Edinburgh - covid Dec 20, long covid diagnosed Feb 21. GP has stated there is nowhere else for me to go and now I should view these as Lifelong. Self-management pathway similar to ME clinic (I have had ME for 18 years) and so seen as not worth it for me personally (GP suggested this). GP unable to access any appointments for me re: developing post covid Raynaud's. In the year 2021 I was diagnosed with pattern breathing disorder (from Respiratory) with zero follow up; I was given a place on a medical trial where FND was diagnosed and managed to get on another medical trial to get neurophysiotherapy, but no follow up since Jan 22. Social care has been involved for equipment but all care being done by family. GP and I have discussed openly how different LC is to my experiences of ME but that Lothian is solely focusing on fatigue management and as yet ignoring all other aspects. We discussed that HR/BP inconsistencies (some of which are dangerous) are not urgent enough for investigation. Do not blame my GP for any of this, he is doing his best - these pathways just aren't for people who had ME previously or for those who aren't urgent.'

- ‘No support since 2021. Got Covid April 2020 was referred to ME clinic and respiratory clinic both short term and before 2022. Only referred because I kept going back to GP pleading and begging for help. Frustrating as each time would see a different GP (no continuity of care, which for any long term condition should be standard). Some GPs awful, didn't believe or know anything about LC and I was burdened with having to educate them whilst being so ill. Had one GP suggest ME and referred me to that clinic after all standard tests were completed. After ME clinic was done, I was still struggling with symptoms and kept going to GP and was referred to respiratory clinic. GP still has no knowledge of LC and when I ask for treatment options says there is none. GPs not aware of any support services and my surgery not part of the LC trial. When I ask for tests, GP keeps saying there are no existing pathways for tests even. Feel like I'm locked out of the system.’
- ‘West Lothian. Suspected Covid pre-testing 2020, 2nd infection Nov 2020, 3rd infection Jan 2022 leading to Long Covid & ongoing symptoms. Unaware of any of these. No onward referrals from GP and have pretty much been told I need to ‘keep it till it gets better’.’
- ‘Edinburgh. Ill since March 2020, fought hard for every referral but they are all long waits for short dead ends (hope you know what I mean by that) that didn't lead on to any kind of meaningful rehab help. ME services at Astley Ainslie were still very much CBT and GET and fatigue management this year even despite changes to NICE guidelines and totally useless after living with this for nearly 3years and having figured out on my own. CHSS phone line is lovely tea and sympathy but not much else unfortunately the few times I have phoned. Not aware of any of the other stuff but it doesn't sound promising for those of us who have been ill for years and figured out the basics of self- management ages ago. Very disappointing.’
- ‘Been seeing my GP since I first developed symptoms in Summer 2020 and she's been great at referring me to specialists to have tests but the specialists have no clue about Long Covid or any understanding of how it interacts with their specialism. This has led to a specialist (who didn't think my new rheumatism had any link to LC) to prescribe me high intensity training exercise which, surprisingly, caused me to collapse. Haven't at any point been told about digital self-management tools of the advice line but I'm very sceptical that either would provide meaningful help to my symptoms.’
- ‘I saw GP and Neurology last week. Both confirmed nothing that can be accessed in Lothian via pathway. Almost a full year after funding, all I'm seeing is some lived experience tokensim, a bunch of meetings being cited as an achievement and not much real transparent delivery or accountability”

- ‘Lothian does not have any specific Long Covid services and what they’re bringing is of no use to anyone who has been unwell as long as we have. My GP has struggled to find relevant services, finally referring me into MECFS. It’s ALL remote and advice based. Their original referral pathway was utterly flawed and didn’t do proper assessments back in 2020. Their only designated clinic at the moment is the LC memory and cognition research clinic - run by the FND team and I’m deeply suspicious of their motives in trying to diagnose so many of us with FND without adequate diagnostics. This is something even FND experts are concerned about. Lothian is NOT doing appropriate diagnostics for some conditions in some consultant clinics - e.g., PoTS. Some services are insisting equipment is self-funded (untrue). You also must meet criteria for referral to many services, e.g., Respiratory etc. My chest is playing up again, but I’ve given up mentioning it to my GP. There is no point. Likely no point in asking for Ortho or Rheumatology to see me and give me an MOT. I have had to go. I’ve had two diagnoses which need further medication, but I need to chase up the letter. Basically, unless I’m prepared to use the limited reserves I have on private treatment etc, I am not getting what I need. Only service I am positive about is Gynae oncology. They’re amazing. Everyone in Lothian - would you be up for a group complaint about our experiences? Happy to facilitate a group meeting to discuss. We can involve our MSPs.’
- ‘I had suspected COVID before official testing and never really recovered. I was told there is no such thing as long COVID. I got COVID for second time 15/1/23 and still symptomatic waiting on Dr phoning me, not getting my hopes up.’
- ‘Can you provide initial link for allocation of funds to NHS Lothian to see what services are available? As you are aware, NHS Lothian withheld to Long Covid Clinics as was deemed to be unable to support because of staff shortage.’
- ‘Edinburgh (my GP practice not in the trial group). Initial covid infection March 2020 a week before lockdown. LC symptoms started June 2020 and I didn’t go to GP until desperate. He diagnosed LC by November and gave me a helpline number. By the time I called it, it had been discontinued and turned into a triage line. I was sent to Occupational Therapy where I was offered a regular phone call by March 2021. That has been the one consistent support of self-management, support dealing with work when I went back and a sympathetic ear. GP referred to Respiratory, who ran breathing tests (some I couldn’t manage to do). Said breathing pattern disorder but couldn’t refer to pulmonary rehab as it had ‘collapsed under pressure of covid’. Referred to Cardiology for chest MRI and ECG – ‘normal’. Excruciating chest pain and SOB continued. Months passed, GP said Respiratory will have a plan for you. Eventually phoned Respiratory - and they’d signed me off. Asked for a further appointment and the consultant said Long Covid was not in his remit, he didn’t have time to study it, go back to the GP. Inferred I had wasted his time. GPs (never the same one twice, and under pressure from me) have made referrals since to Chronic

pain, ME/CFS, and Neuropsychiatry, also Ophthalmology via my optician, all have signed me off saying nothing more to offer, though I think I have been referred for Cognitive Rehab (4 months and waiting). Exhausting telling the same story over and over, travelling all around and coming across medical gaslighting, dismissiveness, gender bias and plain uncaring attitudes. Specialists contradict each other. Last but one GP said nothing else to offer. Most recent GP appt for severe ongoing stabbing head pain (migraine?) and chronic cystitis said 'watch and wait'. New symptoms keep coming, old ones come back. Almost 3 years in. No mention by anyone of CHSS (or oxygen therapy, which I discovered and pay for myself and is the only thing I know to have made any difference). I suggest potential tests and treatments – but it's 'no can do' outwith the formulary and the siloed, non-communicating specialists who often know less than I do about how LC interacts with their area. It's been soul destroying at times, but I will keep advocating for myself.'

Most recent comment Friday 24th February 2023

11. NHS Orkney, £14,716

- Support for a specialised physiotherapist who assesses and supports long COVID cases as a significant part of their job plan. This is in addition to support being provided via services already established in the community depending on people's specific symptoms.

Comments from patients within this health board

No comments as of Monday 13th February 2023

12. NHS Shetland, £13,676

- Facilitation of a local pilot to examine whether the implementation of an Allied Health Professional Care-Coordinator role improves outcomes for people living with long COVID.

Comments from patients within this health board

No comments as of Monday 13th February 2023

13. NHS Tayside, £194,620

- Enhancement of the Tayside long COVID rehabilitation pathway. This pathway will be accessed via an individual's GP in line with SIGN guidelines to deliver an accessible point of access for assessment, support and co-ordination.
- At present, people can be supported by national NHS Inform self-management and the Chest, Heart & Stroke Scotland advice line as well as local services already established across within the community depending on their symptoms. People can also access the community listening service for support.
- Where required, services such as psychology, secondary care teams and local specialist rehabilitation teams, embedded within local communities (including physiotherapy, occupational therapy, psychology, dietetics and speech & language therapy) can be accessed via GPs, depending on what is most appropriate for a person's needs.

Comments from patients within this health board

- 'Thanks for posting. Aware - yes. Used - don't know. I don't think my GP tapped into this resource for my support. Can't access - haven't tried to access. Thanks.'
- 'I'm in Tayside. Aware of the Tayside CARES physiotherapy service for LC rehab. I was referred to their waiting list August 2021. Still on the list. GP hasn't pointed me to any other resources.'
- 'I am Tayside. CARES helpline had no response from them and been phoning since September, and one time I phoned it said taking no new referrals. GP unaware of CHSS helpline. GP frustrated that no clinic in Tayside for her to refer to. Also, she was not sure about out of area referrals. She has ordered no tests and has not seen me yet. Reality on the ground in Tayside is little support, GPs underinformed and unsupported with LC issues. GP unsupported = patient v unsupported. The lack of clearly defined protocols means it is hit and miss, a postcode lottery. I could go on and on so if you want more, please IM me. PS, I note the first point says the covid rehabilitation pathway WILL ... so that sounds like something in the pipeline? Would help if this could be communicated to GPs so they can inform patients. Serious lack of communication.'
- 'One part-time Physiotherapist in Tayside picking up previous CARES patients is all that is available as far as I am aware.'

- 'I have been supported by the Cares Team in Tayside for almost 2 years. I found the service very helpful. My understanding is the service is being phased out due to funding and staffing and if I remember correctly is down to one physiotherapist. I was advised by my employer to check it out, the number was online for self-referral. The Cares team gave me lots of links to online resources like PT for breathing exercises, dietary advice, help with loss of sense of smell and taste and pacing techniques to name but a few.'
- 'Good afternoon, I am in NHS Tayside area, I eventually got a CT scan 40+ week wait thankfully all clear during this wait my GP refused to see me as was in a waiting list for an outpatient appointment. CHAS, contacted me through physiotherapy dept (telephone appointment) to give me breathing exercises said they would follow up with another telephone appointment not happened now well past the 6-8 window I was promised, so it's again down to self-care and pacing myself. PS the monies allocated are a bit on the low side, divide that by the estimated LC sufferers it equals £4/ sufferer!'
- 'NHS Tayside CARES team is no longer operational. I have also just been to my GP to ask about their additional support from govt and they are unaware of anything happening in Tayside. Also recommended painkillers to help with my crash which started on Friday and still going. Really frustrating.'

Most recent comment Monday 13th February 2023

14. NHS Western Isles, £19,988

- Facilitation of Public Health intelligence activity to establish the incidence and need related to long COVID across the Western Isles.
- At present, support for people with long COVID is accessible via general practice, with multiple options available for onward referral in line with individual clinical need.

Comments from patients within this health board

No comments as of Monday 13th February 2023