

Post Covid Assessment services Feedback: December 2020 – January 2021

We invited comments from members of the Body Politic Covid-19 Support Group and the Positive Path of Wellness - (Long Covid UK) Facebook group. Also included are some testimonies from Twitter members. 67 responses were received, of which 61 have been included (January 2021).

December 2020

"There is no long-Covid provision that I have been able to find in my area yet. I am not confident now I could get a referral if there was. In my most recent conversation with the practice, a GP told me that 'everyone's tests were coming back negative anyway' that I needed to 'manage my expectation that there was anything that could be done to help' and that 'the only thing that would make me better was graded exercise'. I have only had 3 telephone consultations in the 5 months I have been ill and am having my first blood test during all this time tomorrow!"

January 2021

"I get impression that some are virtual only and run by physios/OTs who can't offer much more than we are already doing e.g. pacing, diet etc. I'm an OT myself, but feel there should be at least some medical input."

"I was told I wasn't sick enough I have been sick for 11 months now with every random symptom going and hospitalised 4 times!"

"I've been asking my GP and respiratory consultant and they said no - post Covid clinics are only for people who were in hospital on ventilators"

SOUTH WEST

Services:

- ✓ Bath, Swindon and Wiltshire – Wiltshire health and care
- ✓ Bristol, North Somerset and South Gloucestershire – Sirona Care and Health
- ✓ Gloucestershire Hospitals Foundation Trust
- ✓ Gloucestershire Health and Care Foundation Trust

SOUTH WEST

December:

- Positive feedback from Bristol
- Bath: Uncertainty re referral pathways
- GP unaware of any in Gloucestershire
- None further west

"I'm being offered a phone physio appt in Feb that I requested myself by chasing the local respiratory team. There is supposed to be a Bath, North Wiltshire and Swindon NHS long Covid service according to the press release but my GP and I haven't been able to locate a referral pathway. Not sure it exists." (Bath)

SOUTH WEST

January

- Still no clinics in Gloucestershire – service not yet started
- No clinics in Dorset, Devon, Cornwall
- Patients being offered graded exercise
- Bath/N Wiltshire – patient referred in October, appointment not likely until end March/April

"Was referred to Bristol...They said I'm not in their catchment area. There isn't another one for many miles away"

"No link with other specialities for investigation of ongoing symptoms."

WEST MIDLANDS

Services:

- ✓ University Hospitals Coventry and Warwickshire NHS Trust
- ✓ Worcestershire Acute Hospitals NHS Trust
- ✓ Shropshire Community Health Trust
- ✓ Birmingham Community Healthcare Trust
- ✓ Dudley Group NHS Foundation Trust
- ✓ Walsall Healthcare NHS Trust
- ✓ The Royal Wolverhampton NHS Trust
- ✓ Northamptonshire Healthcare NHS Foundation Trust, Northampton General Hospital, Kettering General Hospital
- ✓ University Hospitals Leicester NHS Trust and Provider Company Ltd arm of the Leicester, Leicestershire and Rutland Alliance

WEST MIDLANDS

December

- Birmingham – patient rejected due to absence of signs of infection on X-ray
- Worcestershire: nothing available

January

- Services still not running in Worcestershire
- Warwickshire: service seems to be physio and OH only

"They are all flat out dealing with acute Covid patients plus there are some people off with Covid. She is really frustrated (as are we all). She is still sure that things will happen, but it is proving difficult to bring it all to fruition"

EAST MIDLANDS

Services:

- ✓ North Lincolnshire and Goole NHS Foundation Trust
- ✓ Northamptonshire Healthcare NHS Foundation Trust, Northampton General Hospital, Kettering General Hospital
- ✓ University Hospitals Leicester NHS Trust and Provider Company Ltd arm of the Leicester, Leicestershire and Rutland Alliance

EAST MIDLANDS

December

- No clinic in Lincolnshire
- Nottingham: patient was rejected by hospital, but GP hadn't had any information as to why

January

- Reported that there are no clinics in Nottingham

YORKSHIRE

Services:

- ✓ York Teaching Hospital HS Foundation Trust
- ✓ Harrogate and District NHS Foundation Trust
- ✓ Hull University Teaching Hospitals NHS Trust
- ✓ Sheffield Teaching Hospitals Foundation Trust
- ✓ The Rotherham NHS Foundation Trust
- ✓ Barnsley Healthcare Federation
- ✓ Doncaster and Bassetlaw Teaching Hospitals NHS Foundation Trust
- ✓ Bradford Teaching hospitals NHS Foundation Trust
- ✓ Leeds Teaching Hospitals NHS Trust
- ✓ The Mid Yorkshire Hospital NHS Trust
- ✓ Calderdale and Huddersfield NHS Foundation Trust

YORKSHIRE

December

No data

January

- N Yorks – GP not heard of any nearby: referring to Leeds, 25 miles away
- York: Told may not get referred if CT scan clear. GP can't work out how to refer.
- Sheffield: GP unable to refer – referred to chronic fatigue service but no appt yet.
- Bradford: severe fatigue, received letter from respiratory clinic. Has to be seen by respiratory before able to get appt at 'ME clinic'

NORTH WEST

Services:

- ✓ Liverpool University Foundation Hospital Trust
- ✓ Manchester Foundation Trust (Manchester Royal Infirmary, Wythenshawe Hospital)
- ✓ North Care Alliance (Salford Royal Foundation Trust, Royal Oldham Hospital)
- ✓ North Manchester General
- ✓ Tameside and Glossop Integrated Trust
- ✓ Stockport NHS Foundation Trust
- ✓ Wrightington Wigan and Leigh Foundation Trust
- ✓ Bolton NHS Foundation Trust
- ✓ Lancashire and South Cumbria NHS Foundation Trust
- ✓ North Cumbria Integrated Care Foundation Trust

NORTH WEST

December

- No clinics in either Manchester or Stockport

"My GP and the local CCG have both tried and failed to refer me to a clinic because they say it doesn't exist. That's in both Manchester and Stockport. I'm at a loss what to do. It depresses me so much I've given up. I've called, emailed etc numerous times. Nobody has come back with anything useful really regarding a clinic. I have been referred separately to cardiology but that's all."

NORTH WEST

January

- No service available in Cheshire, Lancashire, Cumbria – not accepting referrals
- GPs don't know how to refer
- Manchester GP "never heard of Long Covid clinics"
- Bolton GP contacted CCG/local trust and told none in existence
- Liverpool: GP thought needed a positive test

"I'm awaiting to be seen by the Wigan Covid rehabilitation clinic. I'm currently under the chronic fatigue clinic and seeing a respiratory nurse next week for my 2nd appointment to go through breathing exercises. I've had many tests and bloods and lots of medications prescribed by the clinic and GP."

EAST ANGLIA

Services:

- ✓ East Suffolk and North Essex NHS Foundation Trust
- ✓ Milton Keynes University Hospital NHS Foundation Trust
- ✓ Cambridge University Hospitals NHS Foundation Trust
- ✓ Mid and South Essex- Provide Community Interest Company
- ✓ Hertfordshire Community Service Health Care Trust
- ✓ Essex Partnership University NHS Foundation Trust
- ✓ Norfolk Community Health and Care Trust

EAST ANGLIA

December

- Kent – no provision
- Nothing in Essex – resources going to critical care
- Norfolk: patient got call from LC clinic – referral accepted – will shortly set up tele consultation

"I spoke to my GP yesterday - I speak to her once a month (mainly to renew sicknote and meds), she said again that there are still no post Covid clinics in the area or any in London that she can refer me to. she has me on her list and will let me know as soon as she hears anything"

EAST ANGLIA

January

- Cambridgeshire – patient has been referred to LC clinic but it doesn't yet exist
- Essex – patient not referred to LC clinic. Has had to 'fight' for referrals to specialists.
- Kent – only service is for those with respiratory symptoms - GP willing to refer but no clinic found

SOUTH EAST

Services:

- ✓ Oxford University Hospitals NHS Foundation Trust
- ✓ Royal Berkshire NHS Foundation Trust – Berkshire Long COVID Integrated Service
- ✓ Buckinghamshire Healthcare NHS Foundation Trust
- ✓ Virgin Care Services Limited and Frimley Health NHS Foundation Trust
- ✓ Berkshire Healthcare NHS Foundation Trust
- ✓ Royal Surrey County Hospital
- ✓ East Surrey – First Community Health and Care
- ✓ CSH Surrey and Ashford and St Peter's Hospital
- ✓ Surrey Downs Health and Care Partnership
- ✓ East Sussex Healthcare NHS Trust
- ✓ Sussex Community NHS Foundation Trust

SOUTH EAST

December

- Guildford: clinic has appeared on GP system but couldn't seem to refer – coding fault?
- Isle of Wight: GP filled out referral – waiting
- East Sussex: GP has no info on clinics nearby
- Bedfordshire: Chest clinic were setting up LC clinic but not much happening. Had CT scans. Waiting – doctor suggested GET
- Berkshire: “Told my GP how to refer” – blood tests requested, waiting

SOUTH EAST

January

- Guildford – problematic still, appointments being cancelled and postponed. Tele appt offered for respiratory but symptoms are POTS and fatigue
- GP pleased to be able to refer patients to clinic in Banstead
- Berkshire: very good feedback – detailed self-assessment questionnaire, lung function tests, appt booked. “I really cannot fault my experience”
- Oxfordshire: GP was unaware clinics existed – subsequently referred
- Herts: GP unaware/unable to refer – several people unable to get help as clinics not yet set up

LONDON

Services:

- ✓ University College London Hospital Trust
- ✓ Homerton University Hospital Foundation Trust (Homerton University Hospital)
- ✓ Barts Health NHS Trust, (Royal London Hospital and St Bartholomew's Hospital)
- ✓ Barking, Havering and Redbridge University Hospitals NHS Trust (King George Hospital)
- ✓ London North West University Healthcare NHS Trust (Northwick Park Hospital)
- ✓ Imperial College Healthcare NHS Trust (St Mary's Hospital)
- ✓ Chelsea and Westminster Hospital NHS Trust (Chelsea and Westminster Hospital)
- ✓ Kings Health Partners (Guys and St Thomas NHS Foundation Trust – St Thomas' Hospital)
- ✓ Kings Health Partners (Kings College Health Foundation Trust- King's College Hospital)
- ✓ St Georges NHS Trust (St. George's Hospital)

LONDON

December

- UCLH – very positive feedback
- St Georges: No clinic – according to GP ‘none in south London’
- Barts: “I’m afraid we are not accepting referrals for Long Covid” – clinic not operational.

"In the meantime the patient should be given appropriate advice on graded exercise/ pacing. There are, unfortunately, no other treatments I can recommend at this stage".

LONDON

January

- Problems for patients in Barnet – nothing set up so far. GP “can’t manage the referral process”. One GP thought it was only for hospitalised patients.
- SW London: clinic is respiratory only
- SE London: confusion at GP practice –referral tests done, but no progress
- Chelsea & Westminster: patient still very sick, was rejected because already had specialist referrals to cardiology and respiratory, despite having other symptoms
- UCLH: praise all round apart from those who can’t get referred. One person had negative experience with dismissive doctor who thought he was anxious
- Kings College: GP tried to refer but unable to find clinic on the system – asked patient how to do it. Then told no clinic for non-hospitalised patients

December 2020

Summary:

1. Service very patchy – very few clinics up and running, some seem focussed on acute patients
2. Patients doing much of the legwork and having to advocate strongly for themselves
3. GP's short of information and having trouble locating services and referring
4. Large areas with no service, e.g. South West, Kent, North West
5. Patients still being offered graded exercise
6. Encouraging comments from Berkshire and UCLH

January 2021

Summary:

1. Many clinics still do not appear to be open or taking referrals
2. Some people are being offered inappropriate therapies such as graded exercise
3. A number of respondents express continuing frustration with being dismissed/disbelieved
4. Those who have secured a referral are in many cases having to wait several weeks or months
5. Some GPs are finding the referral service difficult to navigate and do not seem to have been given comprehensive information about local services and how to access them
6. Very little coverage if any in the South West and North West
7. The situation in the South East and London is much better, with frequent praise for the services at UCLH and Royal Berks.