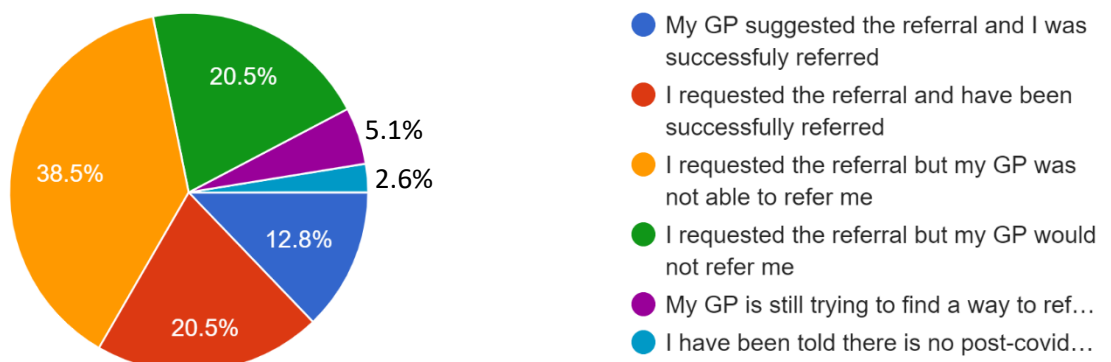


Post-Covid Clinic Survey Report

"I developed COVID-19 on 23 March 2020 and subsequently developed long COVID in May 2020 with post viral fatigue, neurological, respiratory and dermatological sequelae. Although I did not need hospitalisation when I contracted COVID-19 - I did need admission last month for respiratory complications. I am in the shielding cohort (respiratory disease) and identified by NHS England as Clinically Extremely Vulnerable and was housebound from 21 March 2020. Sadly two days into shielding I contracted COVID-19. I am under my respiratory physician and now a neurologist and my GP manages the rest. I cannot find anywhere a post COVID clinic and the NHS website for patients having had COVID is generated towards patients who were acutely clinically ill and not to those who managed at home with either mild or moderate COVID. I have made a FOI to NHS England for a list of clinics - and have had an acknowledgement. I live close to the City of York - and I can get no information from anyone about the establishment of a long COVID clinic. Fortunately my neurologist at my virtual consultation yesterday has referred me to his Neuro Clinical Psychologist as my mental health in terms of anxiety and depression are beginning to appear (having been in shielding for seven months) How can we place pressure on NHS England to share a list of clinics and inform GP's how to refer patients to them (if they exist)? I hope to hear back from you"

What happened after you requested the referral? Please select below the nearest option

39 responses



I requested the referral / My GP suggested the referral and I was successfully referred:

- Hallamshire Hospital - Infectious Diseases Dept
- Warwick hospital – Respiratory Dept
- UCLH (the only clinic flagged by users as ‘multi disciplinary’)
- Brighton (“I have spoken to the post covid hub in Brighton, they are really lovely”)
- Lincoln General – Cardiology dept
- Whittington Hospital – Respiratory Dept
- Royal Lancaster Infirmary (Patient still awaiting appointment)
- St Thomas hospital - Thoracic Medicine Clinic (“After 4.5 months of being ill, my GP finally referred me. I'm waiting almost 2 months for the first phone consult with the clinic - happening end of Sept.”)
- North and East Hertfordshire, Stevenage - Health centre
- Hertfordshire Community NHS Trust: ‘COVID-19 Multidisciplinary Rehabilitation Workforce’ (“was referred by GP in August. Had two session via video call with pulmonary physio. Had one video call in early September with Covid GP as a coordinator. Been referred to fatigue clinic and was checking with neurology re brain fog. I’ve got a face to face on 8 October - not sure what that is actually for”)

I requested the referral, but my GP was not able to refer me

- Addenbrookes (“Can’t prove I had Covid”)
- Barts Health NHS Trust (“My GP did not refer me to UCLH as requested. Instead I had a respiratory referral to my local hospital. The respiratory consultant alerted the post covid clinic to my existence. I have had no direct contact, given any contact details or provided with any guidance from here since mid August. I have no way of following up”)
- University Hospital Coventry (“For a long time they said there was no such clinic. Then they tried again and I'm waiting to hear if I have an appointment with a post covid respiratory consultant, they want me to have an antibody test which I'm fine with, they just haven’t sent me details of how...but since I had a positive community swab test in May it’s is all pointless. I know I have had Covid but because the test wasn’t done in the hospital their systems don’t seem to work. Still waiting on an appointment months after referral”)
- University Hospitals of Leicester (“They didn’t know there was a clinic”)
- Kings, Lewisham & St Thomas's – won’t take people without a positive test swab/antibody or CT showing abnormalities
- Guys & St Thomas’ (“Referral system didn’t reply and link didn’t work”, “I was referred to the Covid Clinic at Guys and St Thomas’ two months ago and haven’t heard a squeak from them. Called them up the other day and no-one had heard of it”)
- Kingston (“I had an over the phone appointment with a respiratory specialist at Kingston hospital at the end of the July. On the letter write up of the meeting it says ‘I have referred her to our Dedicated Multidisciplinary Post COVID-19 Assessment Team’. I rang the department twice to chase this up and I was told I was on the waiting list. I got another call from him today saying those assessments are only for hospitalised patients and I am no longer on the list”)

“My GP said that the Covid recovery clinics were for respiratory only” (south London)

No post-covid clinic in my area

- North-West
- North-East (“I called my local CCG to ask if they knew of anything, I was told they would find out. I got a call back the next day to say they still don't know but haven't forgot about me. I haven't heard anything since and that was 2 weeks ago”)
- Manchester (“Didn't know if any services I could be referred to”)
- Shropshire
- Bristol
- Wales/Cardiff (“Only one in Wales is for people being discharged from hospital”)
- Essex
- Midlands (“Nearest one in midlands is Leicester and for hospitalised only”)
- Birmingham, Worcestershire, Staffordshire
- Stockport (“No covid clinic exists in Stockport.”)
- Bolton (“Unknown if there is one in my area - Bolton.”)
- Slough (“My GP said that there aren't any post covid clinics”)
- Milton Keynes
- Hillingdon (“GP advised no local clinic so unable to refer”)
- Norfolk (“Nothing in Norfolk according to gp”)
- Nottingham
- Surrey (“We have the Mary Seacole centre at Headley Court but that is for post ICU. I wrote to CCG and got reply that would be offering support through existing services: pulmonary rehab, respiratory, CFS, exercise and anxiety clinics. I wrote back re: multi organ disease, need for one stop shop etc but not heard back since”)
- Somerset
- South West
- Devon / Exeter RD&E
- Edinburgh (“just a respiratory physio over the phone”)

I requested the referral, but my GP would not refer me

- Edinburgh (“Won't do any referrals despite now being 6 months on, gave me a leaflet on pacing instead”)
- Milton Keynes (“She's said that it'll just take time or it's hayfever or anxiety so I just need to stop calling.”) – also none in area
- Sunderland Palion Health centre (“never provided a reason.”)
- Bristol (“There is no clinic and the GP has no resources nor understanding of long haul covid”)
- Essex (“My GP doesn't seem aware of long covid/still pushing mental health”)

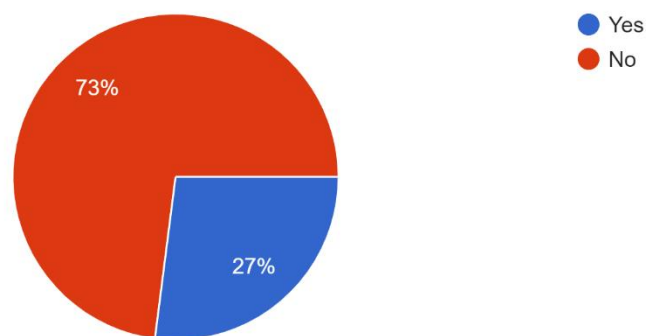
“I asked on two separate occasions to be referred - if there was a clinic. The first time I was told there was not such a thing and the second time I was told they hadn't heard of one but would look into it. That was over one month ago. I am now writing to the practice manager.”

My GP is still trying to find a way to refer me

- AIR service Buckinghamshire (“I was referred to respiratory consultant in Milton Keynes. Respiratory consultant triaged it and sent referral back to my GP practice for me to attend AIR service(?) for a CT scan and PFT. My GP has no idea what or where the AIR service is in our area Milton Keynes. I suspect it is a new service relating to Covid19 but no one knows anything about it!”)
- London (“He said I would be the first one he would refer as soon as one opens”)

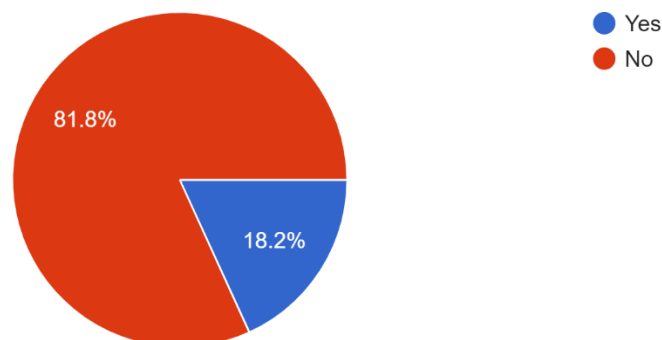
Have you already attended the clinic?

37 responses



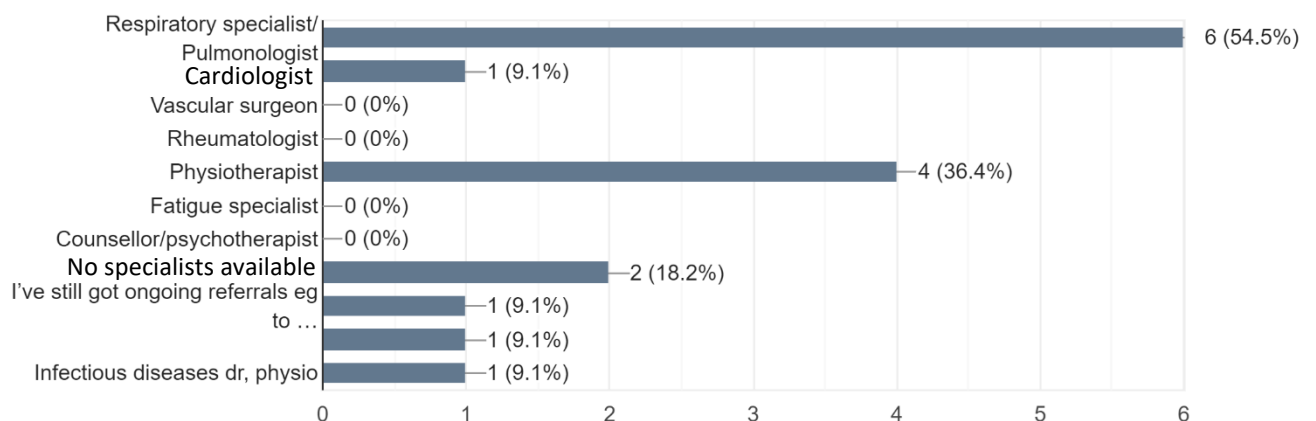
Did you get the impression that the clinic was 'multi-disciplinary': i.e. that a range of specialists were available to assess you?

11 responses



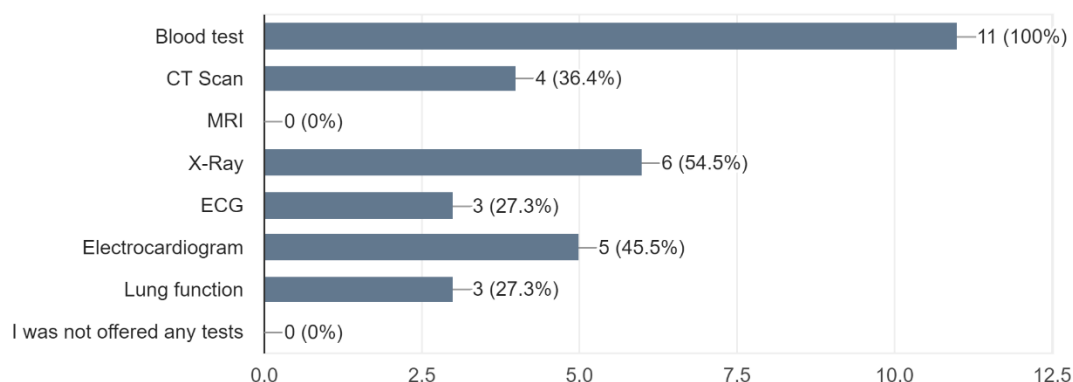
Were you able to see a consultant/specialist? Please tick all that apply

11 responses



Were you offered any tests?

11 responses



If you were offered blood tests, can you list any non-standard tests you may have had?

UCLH:

Procedures • Renal Profile (Na, K, Creat) • FBC and Differential • Liver Profile • NT-proBNP • C-reactive protein • Ferritin • vWD Screen (von Willebrand) • ADAMTS-13 Activity • ESR • Creatine Kinase • D Dimer • Coagulation Screen (Without Fibrinogen) • COVID-19 Antibody test (Serology)

Hallamshire Hospital Post-Covid:

D dimer, troponin, liver enzymes

Please add any other information about your referral and experience at the clinic here:

UCLH:

"My appointment lasted 4 hours and the doctor listened to every symptom I had and are still suffering with. She was incredibly helpful and interested and wanted to do everything she could to

help. It changed the course of my recovery on that first appointment from feeling helpless and alone to feeling like I'd been seen and believed. It was incredible."

NHS Whittington

"The radiography department specifically looked for small clots in my lungs due to my long covid status, and one was found as a result of their diligence."

Hallamshire Hospital Post Covid

"My GP wasn't even aware of the post covid clinic I had to find about it myself, when I called them they told me it didn't exist although I knew somebody that was already seen there. They didn't want to see me, only wanted to do a phone appointment I had to push to be seen in person to get bloods done."

From Twitter: "Thought they were just at the end of a rainbow 🌈?"