



LONG COVID 'EXPLORING UNMET NEED'

MEETING HELD JANUARY 9th, 2023.

**Healthwatch Hackney
Patients' Forum for the LAS**

Speakers

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Long Covid Engagement Lead, City & Hackney COVID
Rehabilitation Service (CoRe)**

**Sally Beaven, Acting Director of
Healthwatch Hackney**

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Chair of Patients' Forum for the London Ambulance
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Healthwatch Hackney is your local health and care watchdog.

Our vision is of a Borough where health and social care provision is equal and accessible to all; where services are of the highest quality and meet the needs of all Hackney communities and where residents are at the heart of the design, delivery and improvement of health and social care services.

Our mission is to improve health and social care provision and outcomes for people in Hackney by working to ensure that treatment and care are provided with respect and dignity, valuing diversity, encouraging participation and working together. We do this by being the independent champion for residents and people who use services ensuring the voices of people across the Borough are heard in order to influence decision makers.

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PATIENTS' FORUM

FOR THE LONDON AMBULANCE SERVICE

The Patients' Forum monitors the LAS and other urgent and emergency care services across London.

Our members are local people who examine services both as users and active lay people. We obtain the information we need to monitor health services from the LAS, the Commissioners and NHS services across London. The Patients' Forum monitors all London Ambulance Service activities.

The Forum raises awareness of the needs and views of patients and the public and attempts to place them at the centre of health service decision-making.

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INTRODUCTION

Long Covid has been shrouded in mystery as people suffering the wide range of symptoms and healthcare teams, struggle to understand the cause, care and treatment for this condition.

Many lives have been put on hold and families suffered hardship as the more severe symptoms cause 'brain fogging', difficulty in living a normal active life, inability to work and symptoms that sometimes cause pain and apparent depression.

We are very grateful to Amina Ed-Deen and Sally Beaven for their excellent presentation and Stephanie Poulton for her CoRe leadership and support for our meeting.

The meeting aimed at exploring unmet need for local people with this devastating condition, the impact on local people and how their needs might be better met from both a healthcare and financial angle.

Understanding the barriers faced by many people to getting treatment, and particularly people from BME communities, is of fundamental importance.

We hope that the City and Hackney Long Covid Survey will provide insight into how people are being impacted by Long Covid, and that the Integrated Care System will ensure longer term funding of the CoRe service so that they can continue their excellent work for local people suffering the effects of Long Covid.

Amina Ed-Deen
Long Covid Engagement Lead
City & Hackney COVID Rehabilitation Service (CoRe)

Presentation:

https://www.patientsforumlas.net/uploads/6/6/0/6/6606397/long_covid_inequalities_p_p_las_patient_forum_jan_2022-5-1.pptx

As the Covid Rehabilitation Engagement Lead, my role involves creating a partnership with voluntary sector organisations, Healthwatch, the Local Authority and other stakeholders within the community, to increase awareness of Long Covid and to increase the support available for patients suffering from Long Covid.

The definition of Long Covid includes symptoms that could develop within the initial infection stage and then continue beyond a 12-week period. There are over 200 documented symptoms, the most common being fatigue, breathlessness, fast heart rate, palpitations, chest pain, brain-fog, lack of concentration, as well as muscle aches and pains.

The Office for National Statistics (ONS) reports that 2.1 million people in the UK have self-reported Long Covid symptoms – just over 3% of the population – as of October 1st 2022 (ONS 2022).

We have observed within City & Hackney the impact of health inequalities on access to CoRe services and this is reflected across pan-London data.

CoRe services include:

- Occupational Therapy
- Cognitive Behavioural Therapy (integrated with IAPT LTC)
- Psychological Wellbeing Practitioners (integrated with IAPT LTC)
- Physiotherapists- both musculoskeletal support and respiratory therapy
- Administration – booking, counselling, appointments and referrals
- General Practitioner – on a part-time basis
- Respiratory Consultant
- Access to Secondary Care specialties, e.g. Cardiology, Gastroenterology, Neurology and Rheumatology
- A&E direct referral
- Access to neighbourhood voluntary sector support services

**IAPT – Improving Access to Psychological Therapies
LTC – Long Term Conditions**

Long Covid Service Pathway:

When a patient/resident reports having symptoms believed to be Long Covid, or other unexplained symptoms, the first point of contact within the NHS is through their GP. There is currently no other method of self-referral, although this is now being worked on to make the referral process smoother and easier.

The GP will carry out a range of tests to exclude the possibility of other causation. This will determine whether the patient is referred for specialised care. If referred to CoRe, the patient is offered an 'introductory session' and shown what support can be given – and is then offered the opportunity to 'opt in' or 'opt out' of the service.

If patients 'opt-in' they will have a multi-disciplinary team assessment. This is a two-part assessment, either face-to-face or 'virtually', depending upon the patient's preference. However, CoRe do prioritise seeing patients face-to-face as this proves to be more effective and allows them to talk more freely about issues of concern.

At the end of the assessment, a 'tailored plan' is developed according to the symptoms they have presented with, and the things that they are struggling with most. This will ascertain whether the patient should be referred to an individual therapist/practitioner, or whether group-based therapy would be best. The patient can then decide what feels is best.

The Service Background

There is a large disparity in the patient demographic of CoRe service users. Currently approximately:

- 73% have a white ethnicity
- 14% black and ethnic minority groups
- 8% mixed/other

Work is now being undertaken with local stakeholders to understand this demographic. The City & Hackney population data is 62% white ethnicity and 38% black and minority ethnic groups.

CoRe will try to find ways to improve the access and referral process to CoRe services. It is possible that there may not be enough awareness of CoRe in local primary care services.

Long Covid Inequalities in City and Hackney

There is a significant lack of inequalities data, in relation to Long Covid in City & Hackney. We know that Covid has impacted black and Asian minority groups more severely than others. However, we are not seeing that in terms of who is accessing CoRe services and we know users of the CoRe service are not representative of the local population. We want to try and change that. We want to better understand how we can improve access to CoRe services and reduce any barriers that impede access.

Services and Barriers e-Survey

The rationale behind this e-Survey is to better understand the barriers facing residents of City and Hackney, when seeking help or treatment for Long Covid, and how to identify areas of unmet need in order to plan better health services for residents.

The e-Survey is 'live' to any resident with confirmed or suspected Long Covid. The Survey takes approximately 10 minutes to complete.

Residents can call or email the CoRe service if support is needed to complete the Survey. CoRe will return calls, and with consent, a team member is happy to complete the form on the caller's behalf.

Participants can also opt to enter a prize draw for a chance to win a 'store voucher'.

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Sally Beaven
Acting Director Healthwatch Hackney

Presentation

https://www.patientsforumlas.net/uploads/6/6/0/6/6606397/long_covid_sb_presentation_for_jan_hw_patient_forum-4.pptx

This is an opportunity to share the e-Survey findings so far.

The e-Survey started in December 2022 and continued to run through January and February 2023.

We had planned to undertake some interviews with people who have experienced Long Covid, in order to try and understand what the barriers were to accessing CoRe services.

We have had so many people come forward to take the Survey, because this is obviously a really important topic to many people.

210 people with Long Covid symptoms have completed the Survey, with 90 people expressing an interest in being involved in further discussions, interviews or focus groups.

We also plan to hold two large events in which participants will be divided into smaller discussion groups. This will allow us to understand more about people's experiences of Long Covid and allow us to dig deeper.

We shall explore all the barriers to the accessing our service. Some people are not even getting as far as seeing the GP to discuss Long Covid symptoms.

The following data is derived from the 210 people who filled in the e-Survey

Procedures	Percentage
Tested 'positive' for Covid-19	82%
Did not test 'positive' for Covid 19	17%
Received medical advice/treatment from their GP	50%
Received advice from Pharmacy services	15%
Received medical advice from NHS 111	26%
Did not seek medical support	13%
Number with Long Covid admitted to Hospital	43%

Long Covid

The experiences of the 62% (124 people) reporting they had been diagnosed with Long Covid, were as follows:

Symptoms Experienced	No. of People
Diagnosed with Long Covid	124
Fatigue	114
Difficulty in concentrating	113
Problems with memory	83
Shortness of breath	82
Muscle aches	94
Heart palpitations	47
Body pain	74
Other symptoms	46

Impacts on daily life:

Impacts on daily life for those suffering from Long Covid:

Impact on Daily Life	No. of People
Difficulty in caring for their family	63
Unable to work	79
Having to ask employer to make reasonable adjustments	78
Unable to attend education	25
Having to take a break from work/education	75
Difficulty in socialising with friends/family	85
Other	33

We heard of other ways that Long Covid is impacting on people's lives:

Cannot live a 'normal' life
Being completely bed-bound
Lack of motivation – to exercise, maintain house/tidiness/hygiene, etc.
Inability to pay rent as unable to work
Effects on social life
Feeling debilitated
Lack of understanding from family/friends/colleagues
Experiences poor insight into Long Covid and discrimination

Language barriers

Responders were also asked if they thought communication in their own 'language' might have made it easier for them to find and use appropriate services and get help, when experiencing Long Covid symptoms:

Language Barrier	No. of People
Yes	61
No	95
Maybe	36
Not sure	11

Of the 61 people stating that language was a barrier, many had English as a second language.

Others, with English as their first language, reported 'brain-fog' causing them to struggle to express themselves, therefore, in a way, language and communication was a definite barrier.

One respondent reported that having autism was a barrier to communications.

Within one of the questions about language, we noted there are two parts ... the language one speaks and the difficulty in communication when feeling unwell.

Disability or Long-Term Conditions

We asked respondents if they were living with a disability or Long-Term condition that could adversely affect their ability to come forward and engage with services. Of the responders, 74 told us that they were living with a disability and/or a long-term condition. Some of the disabilities identified were:

Breathlessness
Difficulty in using public transport
Unable to leave the house
Unable to climb stairs
Unable to stand or walk for long or far
Impact on life activities
Fear and anxiety

Reasons given by patients with Long Covid symptoms for not accessing Long Covid services.

Reason	No. of People
Using Public Transport / travelling	28
Finances and expenses	79
Caring Responsibilities	77
Employment	50
Language	17
Unaware of how to ask for help	46
Didn't think there is anything would help	46
Have tried to find help but was unsuccessful	49
Knew someone that tried to find help and had a bad experience	29
Other	11

Some of the worrying findings will be explored in more detail by the CoRe team and at the planned events - including the possibility of offering free transport for people to come and engage with the CoRe service.

Demographics

Half of the people we spoke to with Long Covid were from BME communities, and half had a white ethnicity.

- Most of the responders were between the ages of 21 to 60 years
- More women than men were coming forward to talk to us
- Half of the respondents were in employment and the other half were unemployed.

We are grateful to all those with Long Covid who took part in the Survey.

This is an on-going piece of work and the next step – once we have completed gathering the data – will be to analyse the result in terms of whether there is a particular group of people reporting particular barriers to accessing services – or whether there is a particular group of people who find it easier to access support.

QUESTIONS / ANSWERS and FEEDBACK with AMINA ED-DEEN

Question from Chelliah Lohendran

You mention that many white British people have sought your services, but that the BME groups are the most effected by Long Covid.

What is stopping the BME groups with Long Covid accessing your services?

If we contact the Primary Care Networks (PCNs), would they be able to give some data on why BME communities are not accessing the CoRe services?

Answer:

Covid-19 disproportionately affects BME groups, therefore logically and statistically there must be a considerable number of people in BME populations suffering from Long Covid who are not accessing our services. We want to know why.

It is proving quite hard to get our Survey 'out there' and to enable people from BME communities to share their experiences of barriers to accessing care.

Perhaps, when visiting the GP, they were not listened to! This could be the reason we are not seeing a significant numbers from BME populations coming to our services.

We are working with local community groups to contact residents directly and to get this Survey circulated. One would think that GP Practices and PCNs should be able to get more data for us.

It seems that some BME groups are not seeking care and are, therefore, missing from the data.

QUESTION from Stephen Sartain

Long Covid is becoming a specialist area. Is there training for Care Workers and people in the Hospital environment? There are many different symptoms of Long Covid and, therefore, different ways to identify it.

- Are GPs having problems making referrals to the CoRe service?
- If someone from a BME background visits their GP with Long Covid symptoms, is the patient being referred to the most appropriate service? We know that GPs are 'snowed under' at the moment.
- Is Long Covid considered to be a 'disability'? What are the consequences when people lose their jobs as a result of Long Covid and do they get benefits.

Answer:

Long Covid can be a very individualised experience.

The most common symptoms are those of fatigue, breathlessness, chest pain, muscle aches and pains. They impact in a different way each person on a very individual basis. Some people are experiencing severe symptoms, whilst others are coping somewhat better.

In every case, these symptoms impact on their lives or their daily activities, and there is no standardised formal training for GPs and primary care teams. However, we do recognise that this is an issue.

The impact on carers of people suffering with Long Covid, and family members or friends, is profound economically and socially.

My role is to try to identify the support we can provide, even if it is just information or signposting.

As an Engagement Lead, one of things that I am working on with other stakeholders, is to offer training and workshops...this could include information workshops on whatever the patient or their families feel is most important. This ties in with welfare and financial support.

The development of services has been very slow. I only came into this role in May 2022, so I am trying to do what I can with the funding from the Government that we have - and the uncertainty of how much longer the service will be available.

We are waiting to find out if we have funding for a further year, so we are unsure what support we can offer as a specialist service - we need to know that, in order to support families and patients in City & Hackney.

I don't think my role exists in the other North East London Boroughs I don't think that Tower Hamlets Long Covid Service has an Engagement Lead focusing on these issues. Nor does Barking and Havering, although they are seeking funding for this type of role.

In terms of training, when patients are referred to us, we identify their needs and how their symptoms are affecting them, so we can then do our best to support their needs, but in the terms of a general kind of training programme, there is not anything yet, sadly!

As far as the referral process via the GP is concerned, we are working closely with the GPs whilst understanding that they are under immense pressures.

We have provided a training programme for GPs and Practice Nurses on the whole referral process, and the software programs that are used. Much of this is done electronically, so we have made sure that the training is clear and that there are no problems with the referral process.

We also hold webinars for GPs and their staff to keep them updated on the Long Covid progress reports and anything that they need to know when patients approach them in terms of Long Covid being recognised as a disability.

Is Long Covid considered to be a disability?

Unfortunately, we do not have any control over that. It is down to Government to decide. Initially, Long Covid was not recognised as a disability, so many people who could not work due to their symptoms and the impact on their lives did not have a lot of support in terms of finances, or managing their finances. However, very slowly and gradually, this is changing.

We have a Care Co-ordinator in our Team and her role focusses upon supporting our patients to access other support in the community – e.g.: finding/looking for another job or making applications for PIP. We had one patient at risk of being evicted and the Care Co-ordinator provided support in this case too.

It is a government decision whether to classify Long Covid as a disability. We are highlighting just how Long Covid is impacting people and that some people are unable to function normally.

FEEDBACK from Nannette

This is my own experience. I was once a healthcare professional. I have passed 70 years of age. I was having a lot of chemotherapy and then came Covid-19. I didn't even know that I had Covid or Long Covid symptoms, but I was experiencing brain-fog. I began using my brain to do brain games and attending lots of meetings.

Eventually, I saw a Neurologist who told me that I didn't have Dementia or Alzheimers, it was Long Covid. The GP told me that owing to my age, I would have 'to learn to live' with my brain-fog.

Now the problem is about getting psychological support. It is frustrating to have to wait for an appointment and then come out empty-handed. I feel it is better not to go anywhere rather than get this disappointment.

Answer:

Firstly, a GP should not be telling patients that they should learn to live with anything because of their age! However, there is no definite cure for Long Covid, but treatments are available. Research is on-going to find effective Long Covid treatments.

There is more and more evidence from the research that some people are making a full recovery from Long Covid, but significant numbers not making a full recovery.

However, through rehabilitation, psychological support, respiratory support and occupation therapy, patients are learning to manage their symptoms.

As we see and treat more patients, we feel that nobody should have to 'live with it', especially on their own. They need support and we try to help as much as we can with care and treatment.

It seems that 90% of people with Long Covid find it hard to cope. I would encourage anybody experiencing Long Covid symptoms to go to see their GP, ask for the diagnostic tests and ask to be referred to us, if suitable. There is treatment available, and nobody needs to suffer on their own.

QUESTION from Laurell Turner

I work as an Occupational Therapist in Homerton. I have been there for years, and I am now about to move to a Long Covid Clinic in Central London Community Healthcare Trust.

I am interested in hearing further information about your insights from the data given ... about how you are trying to find out what's going on that is leading to the disparity you mentioned, the Survey and the engagement with stakeholders through community groups.

I am also interested in hearing if you have any insights from the data that you have gathered so far.

Answer:

The e-Survey is one of the projects whereby we are hoping to gather some data. We have a Long Covid 'grant scheme' that has been opened up to voluntary sector organisations, in order to provide support and to raise awareness around Long Covid.

These organisations have good standing in the community, and they are the best organisations to raise awareness about the CoRe service and Long Covid, dispel myths, and signpost patients to the services available.

We are working to establish a Peer Support Network, as a lot of our patients who have been accessing our services and been discharged, have told us that there is just 'no longer anything out there' for them.

They find that there is a lack of understanding about Long Covid and what is likely to happen in the long term. This is still an emerging condition and patients are feeling very isolated. Speaking to other people with similar conditions has proven extremely beneficial.

We are learning with and working with other Long Covid services around the country to learn about what they have set up, so that we can establish something better for City & Hackney patients.

QUESTION from Alan Alexander

I am Chair of a PPG in the far North of England. I have four quick questions:

1. You mention that your Team is actually dedicated to Long Covid, or is it just a matter of accessing those specialists, specifically dedicated to Long Covid?
1. Are your meetings with patients face-to-face or by telephone?
2. Concerning the low access figures of ethnic groups, have you looked at the age distribution – comparing white British with other British ethnicities?
3. May I share your slides?

Answer:

We are dedicated to Long Covid, but because of the uncertainty of funding for the next year, it really depends upon the Government's priorities.

Whether we merge with other similar conditions like Chronic Fatigue Syndrome, and other long-term conditions, remains to be seen. For now, we are a stand-alone and dedicated service working with patients with Long Covid.

Our meetings with patients are a mixture of types, but we prioritise meeting patients face-to-face. Sometimes patients opt for virtual meetings.

Across all the different ethnic backgrounds, those accessing our services tend to be in the mid-20s up to 50s. We are seeing only a fraction of people over 50 or above 60.

Please do share the slides (see www.patientsforumlas.net).

QUESTION from Mike Roberts

This Presentation has been very important to many of us. Whilst I am not directly in London, I am a member of Unite Headquarters' branch. Some political colleagues of mine (I am a Councillor) who have had Covid and who work in the NHS, have now got Long Covid.

What does concern me is the fact that the Government is playing 'Patchwork Quilt', again, with regard to responses –'if you can get away with it, don't do anything!'

The pressure is building, and it is going to take some kind of action, particularly to support those with protected characteristics and multiple disabilities.

If you look at the Independent Scientific Advisory Group for Emergencies (Independent SAGE) profile of Covid over the last number of months, it has been an issue for some BME communities to access the services they need and receive timely covid vaccinations.

But the issue with regard to staffing, is that there is a problem with staff who have Long Covid and are still working. There seems not to be a standard level of support within the NHS, and when it comes to communities and their needs, it seems to be that some areas are better than others with regard to functional results.

I am wondering what your thoughts are!

A lot of the issues that I see in Local Government are down to data. If the data is not showing the profile that you expect, or where there are gaps, then the interpretation of that by others, can be very patchy!

In my view, the Government are deliberately looking at certain areas in relation to support where the information is better - and not at all in areas where the information is not adequate. One of the things I think that we need to do, is to share information and data, because Long Covid is not going away.

Answer:

Disparity of service provision and support, in terms of different areas, largely comes down to funding.

It is fortunate that City & Hackney - and our Service Lead, Stephanie Poulton – had the foresight to set up this service in January 2021.

It is likely that if staff in the NHS experience Long Covid symptoms, they are generally managed through occupational health. NHS staff do not generally access our service.

It is vital to share information and data because Long Covid is not going away. We shall be sharing some of our e-Survey's interim results and show what the data is telling us.

We are still trying to push out this Survey and get as many responses as we can, as this data is so important in showing where the need is ... and also when asking for more funding.

We are very fortunate to have the funding to employ a 'Care Co-ordinator' who can support some of our patients, for instance, on:

- How to navigate the PIP system
- How to apply for PIP, and
- How to show evidence of symptoms that are still not classed as a disability and consequently do not enable people with Long Covid to receive PIP.

QUESTIONS / ANSWERS and STATEMENTS – Sally Beaven

QUESTION from Stephen Sartain

Because of the pressures GPs are under, there has been a big campaign recently to request patients to ring the NHS Helpline (111 & 119), or visit a pharmacist.

Could this be a reason why people with Long Covid have not been seeing their GPs.?

I have worked in welfare benefits for over 30 years, and I wondered if anybody had actually applied for Personal Independent Payments (PIP), then received payments or were rejected?

I believe that Long Covid sufferers meet all the criteria required to receive these payments.

It is correct that people with Long Covid are scared of losing their jobs. Concerns are about what the employer will say/do when an employee with Long Covid tells their employer they must take time off work – and whether or not they will get sick-pay.

It is likely that the person will lose their job, especially if they haven't worked there for long. It is frightening enough to have Long Covid and lose one's job, let alone having to apply for benefits.

It might be helpful to put information about the Long Covid Survey/questionnaire in the local newspapers, e.g. Hackney Today. This is issued by the Council.

This would be useful as a way of notifying the public that a Survey and Long Covid services exist, as not everyone has access to a computer.

Another useful newspaper could be the Hackney Gazette.

Answer

That is a great idea to put the Survey in Hackney Today. We shall be keeping the Survey going for a while.

We know that GP access is a huge issue currently. There are bound to be patients who have tried to make an appointment and struggled with not being seen straight away. Many might feel discouraged and have given up.

We are also running a Survey for GPs, to ask them what their experiences of referring into the Long Covid services are, whether they think that the process is working, and whether there is anything that we can do from a Long Covid point of view.

We want to help people suffering from Long Covid to move smoothly through the system. Unfortunately, I do not know the answer to the PIP question. I shall take this back to the Team to see if we can add a question into the Survey on this topic.

Many people are definitely worried about losing their jobs, and when you think of Zero Hours Contracts, there will be many working 'cash-in-hand' and, therefore, unable to apply for sick pay. This will have serious and worrying affects.

Research by Jos Bell who has had Long Covid for 2 years

I first caught Covid while I was chairing a public meeting and again 10 months later. I was extremely unwell for several months and experienced a number of long-term symptoms.

I decided to find out more about Long Covid from international research, and I have made some progress, mostly with self-help, but also with great support from my GP and my Long Covid Consultant at King's College Hospital.

I have also set up a database of international clinical evidence that is emerging about Long Covid.

So many people with Long Covid are fighting to be heard because they may not understand the clinical language used in relation to their symptoms. There is now a lot of evidence coming from international research as to the actual signs and symptoms of Long Covid - rather than it being something vague, where you just do not feel well after Covid and you do not seem to get better.

I am having to live a very different life to the one I had before Long Covid, and a lot of the results from the CoRe Survey have a resonance for me.

I am lucky enough to have a very supportive GP, but many others do not. My Practice has a website which includes a section explaining what Long Covid is.

Some patients feel that their GP just 'fobs them off'; this may be because they do not understand the symptoms and causes of Long Covid. Patients may be fatigued and struggling to describe their symptoms, so they won't necessarily get an appropriate referral to a specialist service.

Internationally, there has been some brilliant research projects, which I have linked into because I needed to know what was going on with me. I could not just sit/lie down and 'give up', so I made use of my networks.

I now have a good understanding of the key elements of Long Covid.

Some researchers have described Long Covid as a vascular disease which involves endothelial damage, which can go on to create further organ tissue injuries.

It may affect the autonomic nervous system resulting in conditions such as POTS - which is why some people feel dizzy. Sleep disruption is also a common factor, and many of us experience tinnitus and neuropathy due to neural inflammation (POTS - postural orthostatic tachycardia syndrome).

There are many Long Covid symptoms because we all react to the virus in different ways, but when specific tests for Long Covid are applied, some common factors do emerge.

Some research projects in South Africa, Germany, and the United State suggest that Long Covid patients have micro-clots.

Autopsies on people who have died of Long Covid suggest that the virus may still be present in some organs months after the person no longer appeared to be infected, and that blood vessel damage is also evident.

One visible symptom of micro clotting is subconjunctival haemorrhaging, and fourteen other vasculature transformation blood biomarkers have also been found to be significantly elevated in one Long Covid study.

There is also a suggestion of mitochondrial damage causing low oxygenation of the blood, and some patients consequently benefit from the use of supplementary oxygen.

Apheresis has been used to treat some patients with Long Covid in Germany, Cyprus and South Africa, but the results are variable (apheresis a technique by which a particular substance or component is removed from the blood, the main volume being returned to the body).

Patients with Long Covid who suffer metabolic disorders may be helped by the use of nutritional supplements. Other patients have used probiotics to restore the natural balance of bacteria in the gut, and antihistamines when suffering from mast cell and T-cell damage. Vitamin D supplements have been used to treat brain-fog. There is a raft of Long Covid symptoms - about 200 identified so far.

All the emerging studies show how complex this condition is and indicate the importance of people getting the help they need in relation to the severity of the condition.

Clinicians in the UK are working hard to find effective treatments for patients, but the Government is failing to engage adequately to develop treatments for Long Covid, and identify biomarkers as Long Covid diagnostic tools.

It is vital that we make the most of international research findings in a collaborative way to prevent Long Covid patients deteriorating and suffering further harm.

Biomarkers are naturally occurring molecules, genes, or other characteristics by which a particular disease can be identified.

Response from Stephanie Poulton to issues raised by Jos Bell

It sounds like the Long Covid meeting was a productive and I have read this report with interest.

Thanks for inviting us to talk about Long Covid and taking the time to write it up. I am sorry I was unable to attend. Amina and I have constructed a response as follows:

Thanks for sharing your experience Jos about the tough journey you have had with Long Covid. Great to hear that you have found support from your GP, consultant and a network to help you to make sense of your own situation.

In response to some of your comments around research – it is an unusual situation with this condition as it has only been around for 3 years, so research into Long Covid, although emerging, is still in its infancy.

It is encouraging that studies are being conducted and published to make sense of what the mechanisms might be that cause the condition and therefore how best to treat it.

The post-Covid services in the UK are linked through networks and NHSE have produced webinars on research updates for clinicians to keep abreast of latest developments, as well self-directed study.

We use the recommendations from NICE within the Covid-19 rapid guideline: 'Managing the long-term effects of Covid-19'. NICE are regularly reviewing the evidence and publishing guidance.

[Overview](#) | [COVID-19 rapid guideline: managing the long-term effects of COVID-19](#) | [Guidance](#) | [NICE](#).

We also regularly meet clinical post-covid networks across London and nationally, to share clinical approaches and experiences, as well as asking questions and supporting decision-making for assessment, pathways and offering interventions.

Within the academic and clinical arenas, critically appraising the quality of research trials is important to determine how much confidence there can be in the results, and the populations studied need to be similar enough to be comparable.

In Long Covid research – there are unfortunately many interpretations of diagnosis, small sample sizes, lack of control groups, recruitment bias, variation of initial illness severity, and variations of time since the start of infection, which reduces how much we can generalise findings to all who may be presenting with Long Covid.

This has been described as a 'Swiss cheese' of evidence (i.e. lots of holes in it). See NIHR Review of Evidence here: [Living with Covid19 – Second review \(nih.ac.uk\)](#).

Studies showing a certain outcome need to have bias reduced, be replicated, and scaled up to increase confidence that a certain treatment is effective and most importantly doesn't exert harm on individuals.

The safety of our patients is at the forefront of the delivery of treatment and so a more robust evidence base is needed to be able to recommend treatments, especially invasive approaches such as therapeutic apheresis.

We agree that prioritising work around Long COVID including further awareness raising, recognition of Long COVID as a condition, and funding of robust research to further understand and refine how it may be diagnosed and treated is needed to help to support those suffering.

We raise this at regular meetings with NHS England as well as contributing to data gathering and raising awareness locally.

We wish you all the best with your journey Jos.

CONCLUSIONS

CONCLUSION by Alan Alexander

Thanks to Amina and Sally for spotlighting Long Covid.

There is quite a parallel with ME, which took years and years to be recognised. ME is, again, a post-viral experience often following Influenza.

We are fortunate that we have the CoRe Team concentrating on this, and probably all the bad experiences for ME patients can enable us to react a bit more rapidly with Long Covid.

ME - Myalgic encephalomyelitis, also called chronic fatigue syndrome or *ME/CFS*, is a long-term condition with a wide range of symptoms.

CONCLUSION by Steven Sartain

Thanks to Jos Bell for her contribution to the meeting. I am now more persuaded – given my Welfare Benefit background - that there needs to be some clarity on what Long Covid actually is, in terms of being a medical disability.

There is clearly a spectrum – some have a very mild form, and others an extreme form.

I will use Jos' information to confirm that Long Covid is a disability, and I think it would make things clearer and enable access to a lot of benefits and help, if it were clarified in this way.

CONCLUSION by Mike Roberts

This has been an incredibly useful meeting – the presentations and discussions have been very helpful.

Great thanks to the speakers, to Healthwatch Hackney, Polly Healy & Alan A.

Thank you everybody for this excellent meeting and for the fantastic contributions. The speakers were outstanding.

Thank you, Kanariya, for organising the meeting and thank you, Alan Alexander for co-hosting and Polly Healy for promoting and writing up the meeting. A great job by all.

Malcolm Alexander

Access to PowerPoint presentations produced by:

1. Stephanie Poulton: Head of City and Hackney CoRe Service

https://www.patientsforumlas.net/uploads/6/6/0/6/6606397/ch_core_update_nov_2022_v02.pdf

2. Amina Ed-Deen: Long Covid Engagement Lead - City & Hackney Covid Rehabilitation Service (CoRE)

https://www.patientsforumlas.net/uploads/6/6/0/6/6606397/long_covid_inequalities_p_p_las_patient_forum_jan_2022-5-1.pptx

3. Sally Beavan – Acting Director, Hackney Healthwatch

https://www.patientsforumlas.net/uploads/6/6/0/6/6606397/long_covid_sb_presentation_for_jan_hw_patient_forum-4.pptx

All the Presentations can be found on the Patients' Forum website:
<https://www.patientsforumlas.net>

RECOMMENDATIONS

- 1) Healthwatch Hackney should raise with the ICS for North East London, the need for continuing funding for CoRe going forward, to ensure that the development / further development of CoRe service and the enhancement of services for all communities suffering from the impact of Long Covid.**
- 2) ICS funding should be adequate to provide transport for patients with Long Covid who find movement and travel difficult, so that they can attend sessions provided by CoRe.**
- 3) That CoRe produces a leaflet for patients with symptoms that suggest Long Covid, to help them to better understand their condition, the treatment and care that is available and how best to access diagnosis and treatment.**
This leaflet should be distributed throughout Primary and Social Care services in City and Hackney and to PPGs.
- 4) CoRe should produce information about the Long Covid service in local languages and distribute through the Voluntary Sector and to local faith organisations.**
- 5) CoRe should produce data showing the rate of referrals to CoRe by each GP Practice in City and Hackney, to help determine which GPs may need more proactive advice and support from the CoRe service.**
- 6) Training course should be provided for social workers, care workers, informal carers, primary care teams and benefits staff, to enable them to understand more about the symptoms of Long Covid and possible treatments and support.**
- 7) Publicise the CoRe Survey and how to access CoRe services in the Hackney newspapers: Gazette, Citizen and Post**

REQUESTS

Please provide a list of community organisations receiving grants to publicise CoRe services.

REFERENCES

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www.independentsage.org/danny-altmann-on-long-covid-in-the-guardian/
- 3) Are some ethnic groups more vulnerable to COVID-19 than others?
Lucinda Platt and Ross Warwick (2020) Institute of Fiscal Studies.
<https://tinyurl.com/4mm23j97>
- 4) Is Long Covid Protected as a Disability Under the Equality Act? (2021)
<https://tinyurl.com/vz7r2255>
- 5) Long Covid and Disability Benefits (2023). <https://tinyurl.com/57rp982c>
- 6) Long-term effects of coronavirus (long COVID) (2022)
<https://cks.nice.org.uk/topics/long-term-effects-of-coronavirus-long-covid/>
- 7) Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK – (2023)
- 8) Estimates of the prevalence of self-reported long COVID and associated activity limitation, using UK Coronavirus (COVID-19) Infection Survey data. Experimental Statistics. <https://tinyurl.com/3cd9yefa>
- 9) Why ethnic minorities are bearing the brunt of COVID-19 (2023)
<https://tinyurl.com/23cbwsz3>