North East London Health & Care Partnership

NEL Community Long COVID Community of Practice: Webinar 1: What is Long COVID?

Laura Graham – Highly Specialist Respiratory Physiotherapist, Co-Clinical Lead Homerton Hospital Long COVID Clinic, HEE Clinical Fellow in Long COVID rehabilitation

Dr Adam Ainley – Consultant Respiratory Physician, King George Hospital – Barking, Havering and Redbridge University Hospitals Trust

BHR CEPN YOUR TRANSFORMATION AND TRAINING HUB

CITY & HACKNEY TRAINING HUB

Newham TRAINING HUB We develop people

TOWER HAMLETS CEPN COMMUNITY EDUCATION PROVIDER NETWORK

Waltham Forest Training Hub Transforming Health & Social Care

Objective of webinar

North East London Health & Care Partnership

- **To discuss**
  - What Long COVID is
  - Overview of prevalence
  - What the hypothesised pathophysiological causes might be
  - Discuss the most common symptoms
  - Consider the possible red flags
- **Case study**
- **Resources**
- **Next sessions**
- **Questions and Answer Session**

Long COVID, Post COVID syndrome or COVID Long Hauler

North East London Health & Care Partnership

Symptoms that remain for over 3 months and at last 2 months in duration

More commonly reported in non-hospitalised patients

Symptoms not explained by any other possible diagnosis

Multiple, overlapping symptoms, likely multi-organ involvement

- 200+ reported symptoms

Prognosis unknown, due to fluctuating nature

Can affect anyone of any age – growing prevalence in children

NICE (2020) Clinical Case Definition: Post COVID Syndrome

North East London Health & Care Partnership

- **Acute COVID-19**: signs and symptoms of COVID-19 for up to 4 weeks.

- **Ongoing symptomatic COVID-19:** signs and symptoms of COVID-19 from 4 to 12 weeks.

- **Post-COVID-19 syndrome**: signs and symptoms that develop during or after an infection consistent with COVID-19, continue for more than 12 weeks and are *not explained by an alternative diagnosis*.

NICE National Institute for Health and Care Excellence

RCGP Royal College of General Practitioners

Healthcare Improvement Scotland | SIGN

The NICE guidelines [NG188]: COVID-19 rapid guideline: managing the long-term effects of COVID-19. Published 18th December 2020

World Health Organisation Post COVID Conditions (October 2021)

North East London Health & Care Partnership

Post COVID-19 condition occurs in individuals with a history of probable or confirmed SARS CoV-2 infection, usually 3 months from the onset of COVID-19 with symptoms and that last for at least 2 months and cannot be explained by an alternative diagnosis. Common symptoms include fatigue, shortness of breath, cognitive dysfunction but also others and generally have an impact on everyday functioning. Symptoms may be new onset following initial recovery from an acute COVID-19 episode or persist from the initial illness. Symptoms may also fluctuate or relapse over time.

World Health Organization

Long COVID Coding:

North East London Health & Care Partnership

Long COVID:

ICD-10CM (U0.9 + specific condition)

ICD-11 (RA02+ specific condition) – purpose of data analysis

Prevalence

North East London Health & Care Partnership

Estimated that between 10-20% of all COVID cases will have symptoms beyond 12 weeks

Self reported 1.3 million people living with prolonged symptoms (>4 weeks)

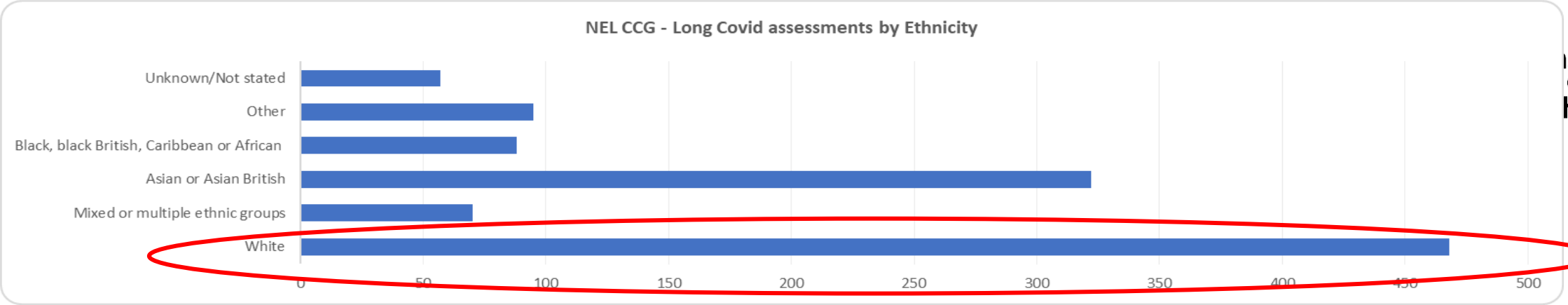
Of these, 71% had symptoms for at least 12 weeks and 42% symptoms for over a year.

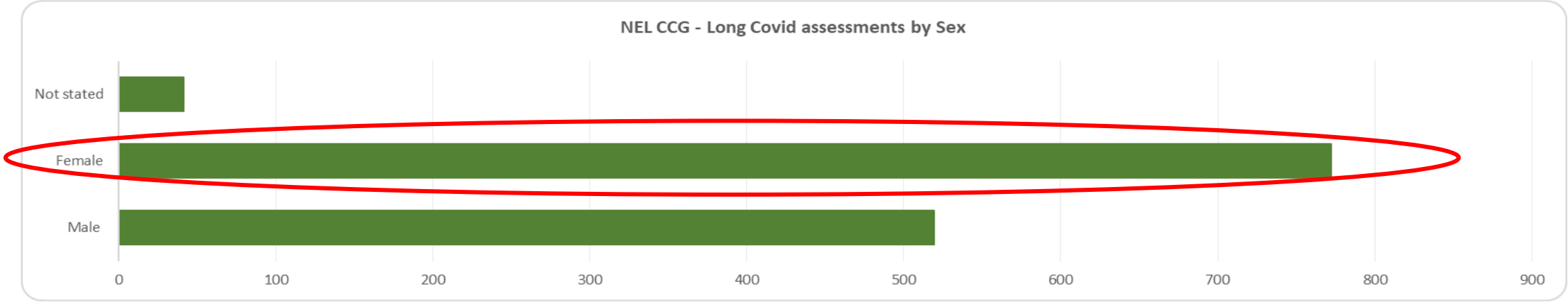
Most reported symptoms: **Fatigue (50%) and breathlessness (37%)**

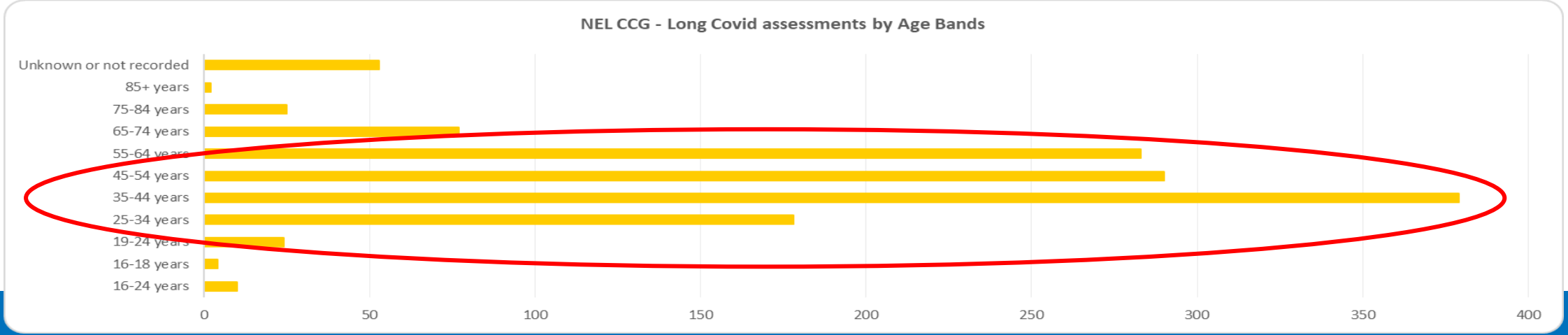
Highest prevalence: *Females, 35-69 years old, deprived, working in health or social care, education and those with activity limiting health condition or disability*

Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK - Office for National Statistics (ons.gov.uk)

st London
Care
hip







Hypothesised Pathological Mechanisms for Long COVID

North East London Health & Care Partnership

- Mechanisms largely unknown
- Possibly related to **long-lasting Inflammatory/immunological dysregulation**
- **Hypothesised that long COVID could be due to:**
  - Inflammatory or autoimmune process
  - Underlying organ damage or scarring
  - Hypercoagulability
  - Persistent clotting
  - Endothelial damage
  - Persistent viral protein

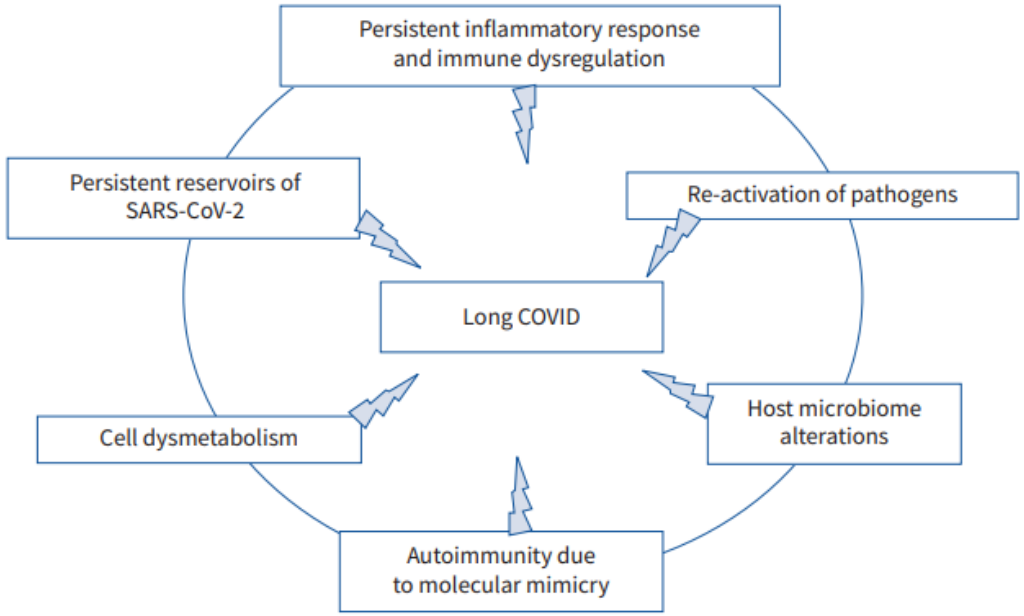
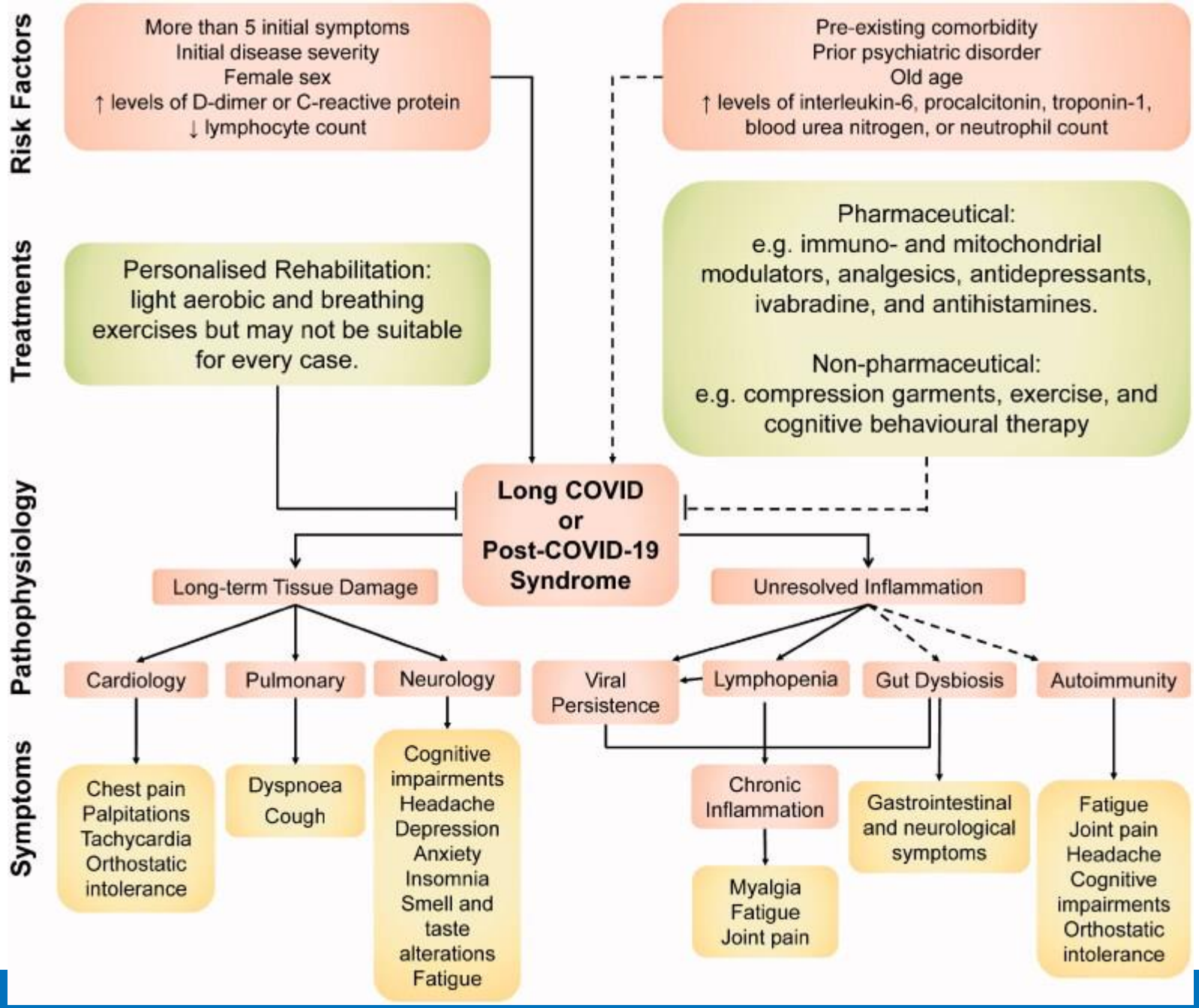


FIGURE 1 Possible concurrent mechanisms leading to long COVID.

Ortona E, Malorni W. Long COVID: to investigate immunological mechanisms and sex/gender related aspects as fundamental steps for tailored therapy. Eur Respir J 2022; 59: 2102245 [DOI: 10.1183/13993003.02245-2021]



North East London Health & Care Partnership

Possible Pathophysiology

Yong SJ. Long COVID or post-COVID-19 syndrome: putative pathophysiology, risk factors, and treatments. Infect Dis (Lond). 2021;53(10):737-754. doi:10.1080/23744235.2021.1924397

Doesn’t just affect adults

North East London Health & Care Partnership

Long Covid Kids & Friends Supporting each other.

If you or your child have had new symptoms for a month or more and think you might have had Covid-19, support is available.

After a Coronavirus infection, many people make a full recovery. For some, the illness can last longer. This is known as Long Covid.

You can have Long Covid after a mild or even symptom-free initial illness. Symptoms can affect any part of the body, can come and go, or new ones can appear weeks or months later.

Common Long Covid Symptoms

ADULTS

- Extreme tiredness
- Shortness of breath
- Chest pain or tightness
- Memory or concentration problems
- Difficulty sleeping
- Fast heart rate or palpitations
- Joint or muscle pain
- Upset stomach or pain
- Changes to smell or taste
- Headaches or dizziness
- Anxiety or depression

Source: NHS

CHILDREN

- Extreme tiredness
- Dizziness
- Rashes
- Brain fog
- Headaches
- Chest pain
- Stomach pain or upset
- Sore throat
- Mood changes
- Joint or muscle pain or swelling
- Sickness or nausea

Source: Centers for Disease Control and Prevention

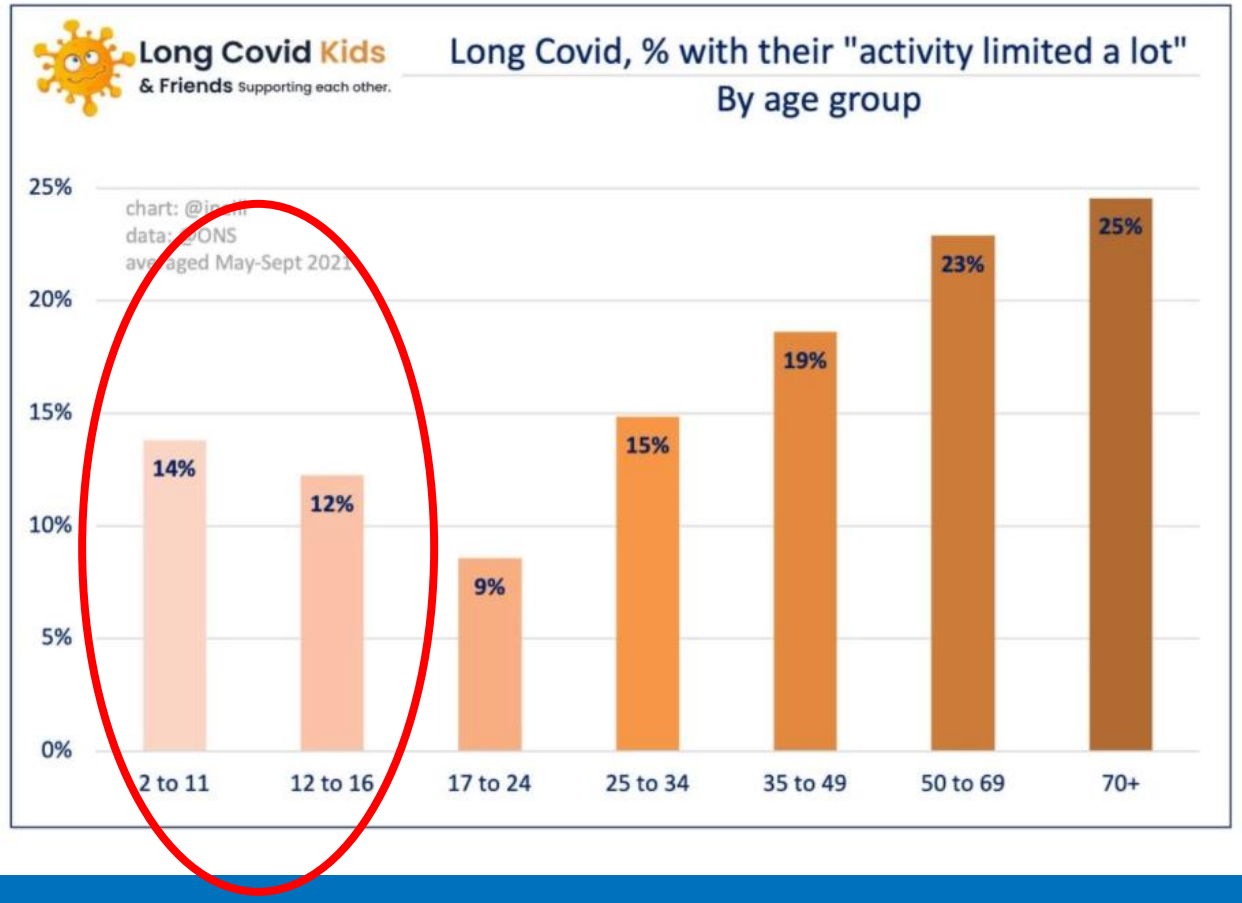
For information and support visit LongCovid.org or LongCovidKids.org

LONG COVID SUPPORT

Long Covid Kids & Friends

Seek medical help if you are worried.

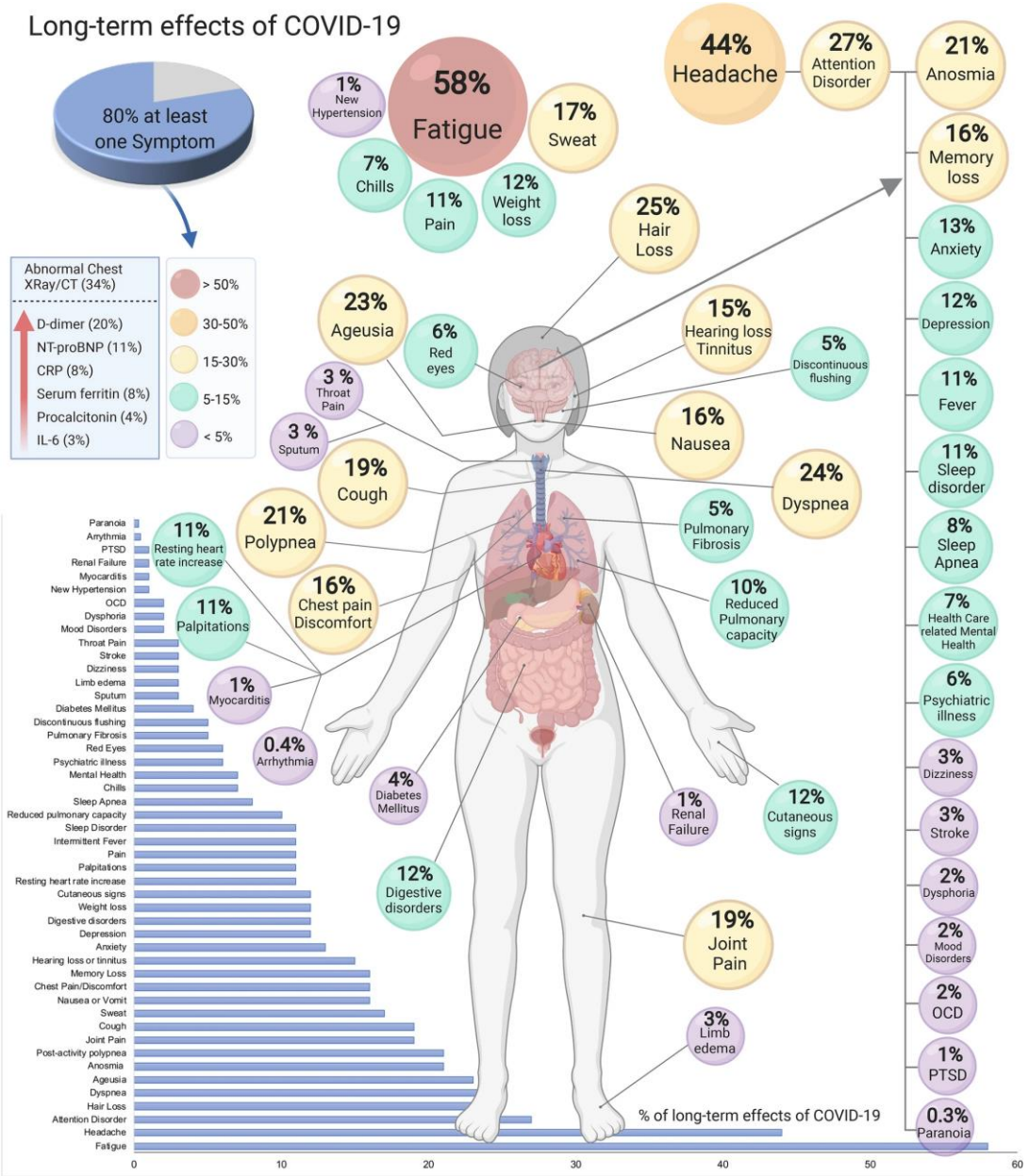
Long Covid Support registered company limited by guarantee (England and Wales) 13422240
Long Covid Kids and Friends registered charity (England and Wales) 1196170
© 2021 Long Covid Support © 2021 Long Covid Kids Published: November 2021



What we do currently know:

North East London Health & Care Partnership

- Long COVID is real, and its important to validate this
- Undetectable on usual tests
- Multisystem, multiorgan, which can mean its fluctuating in nature
- Currently there are no proven pharmacological therapies
- Can affect anyone of all ages
- Likely phenotypes
- Rehabilitation is currently the best treatment offer



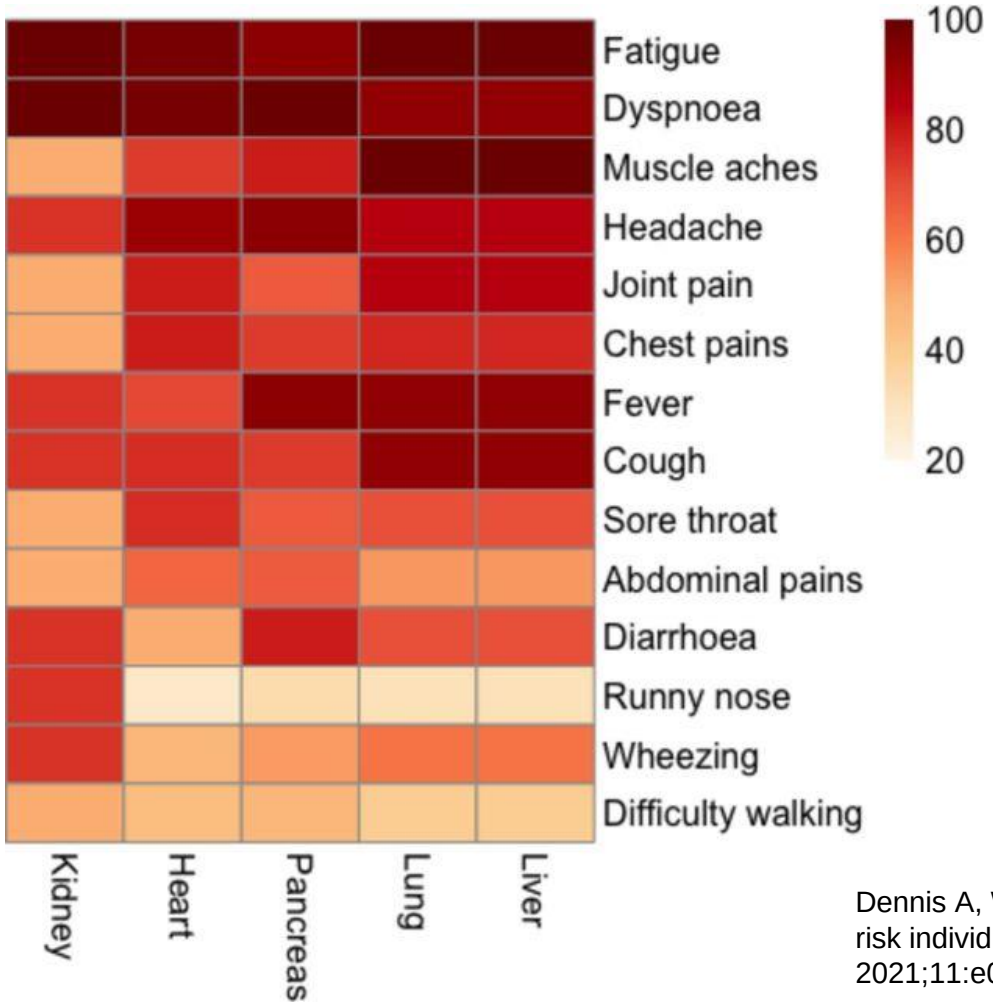
North East London Health & Care Partnership

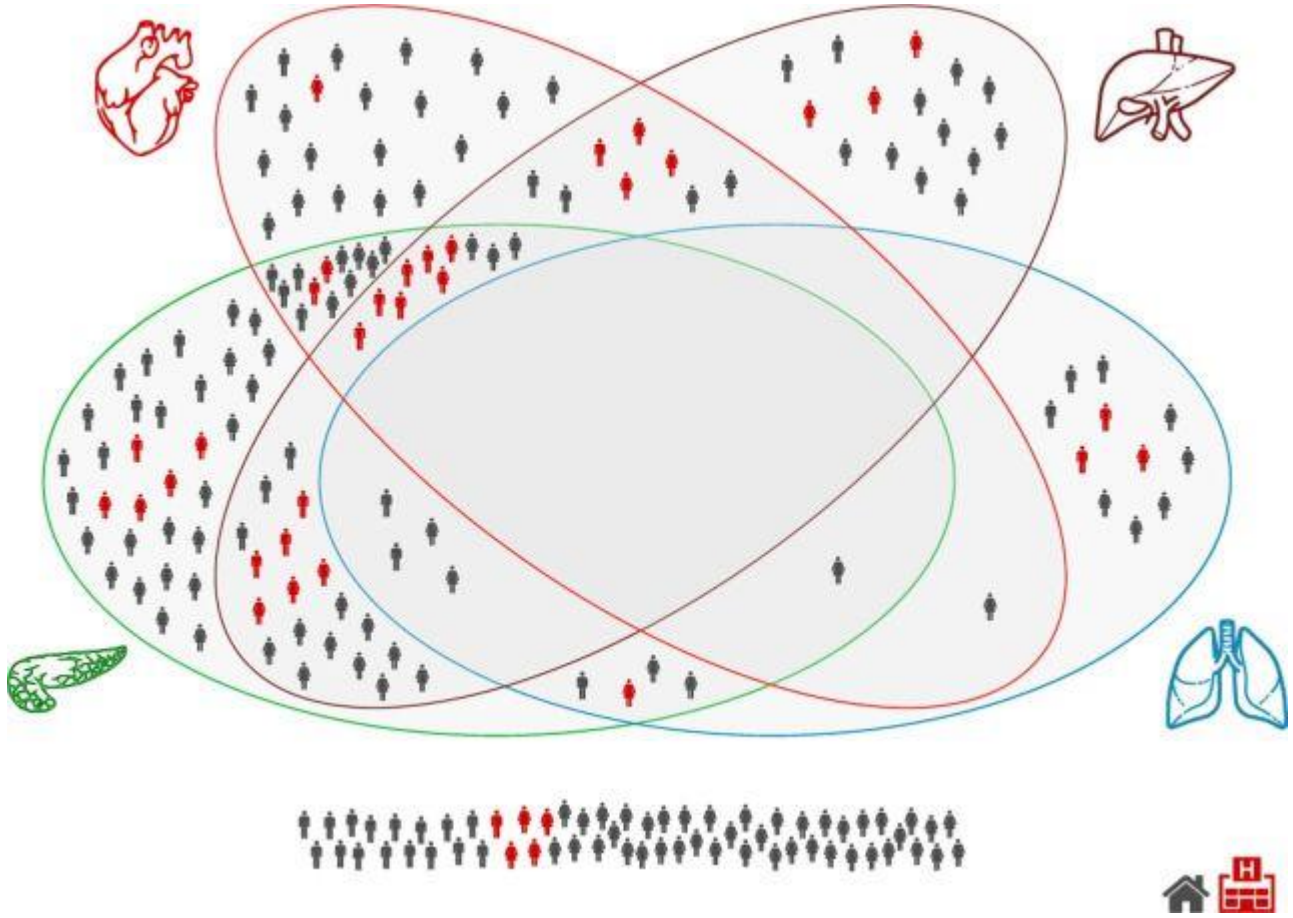
What are we seeing:

- Abnormal breathing patterns
- Evidence of cardiac disease
- POTS/Dysautonomia
- Asthma
- Autoimmune disease
- Hormonal disturbances
- ENT issues
- Psychological difficulties

Lopez-Leon, S., Wegman-Ostrosky, T., Perelman, C. et al. More than 50 long-term effects of COVID-19: a systematic review and meta-analysis. Sci Rep 11, 16144 (2021). https://doi.org/10.1038/s41598-021-95565-8

Multi-organ impairment





Dennis A, Wamil M, Alberts J On behalf of COVERSCAN study investigators, et alMultiorgan impairment in low-risk individuals with post-COVID-19 syndrome: a prospective, community-based studyBMJ Open 2021;11:e048391. doi: 10.1136/bmjopen-2020-048391

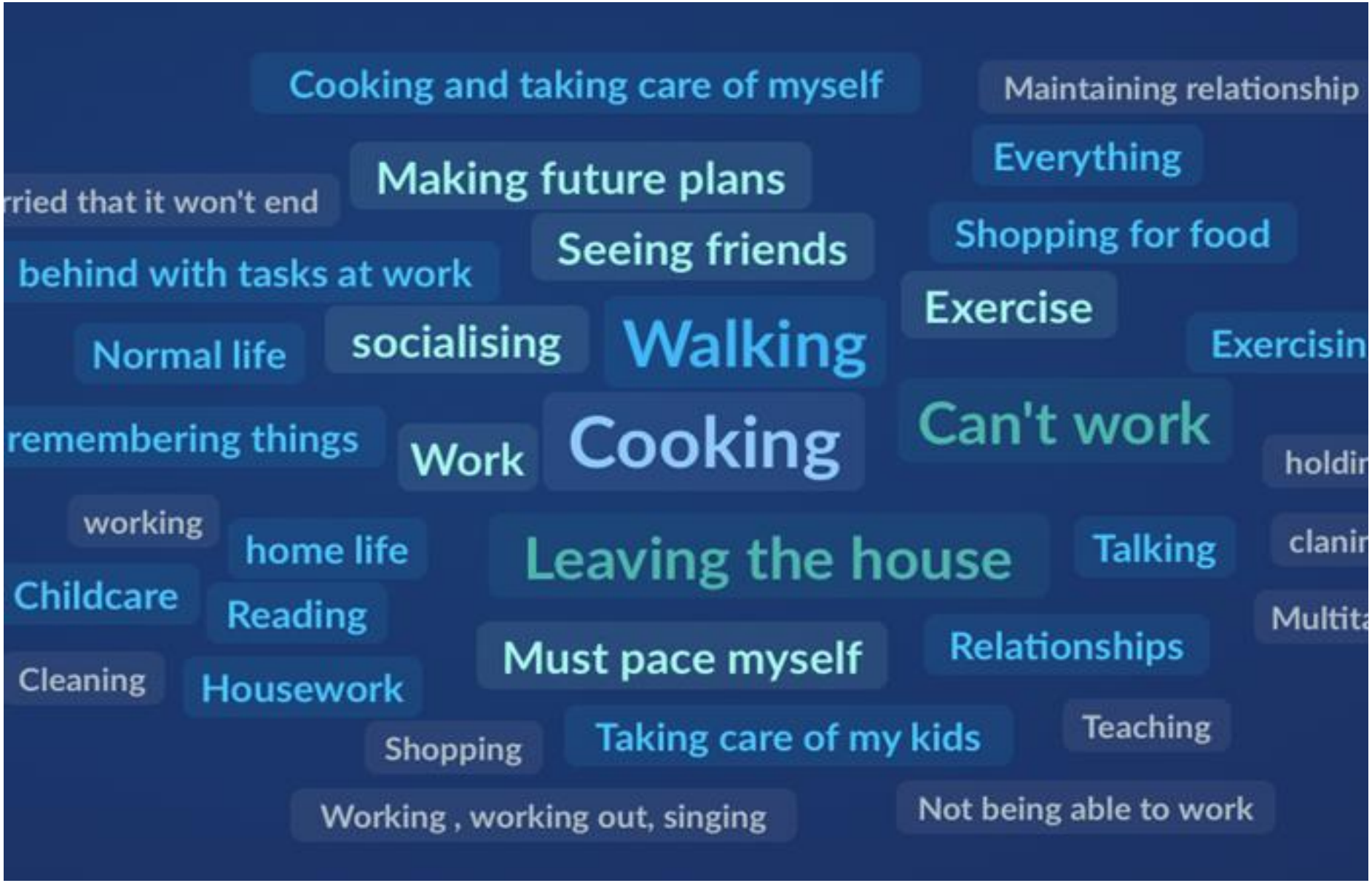
CoRe

North East London Health & Care Partnership

CoRe

City and Hackney COVID Rehabilitation Service (CoRe)

Introductory session



North East London Health & Care Partnership

CoRe

North East London Health & Care Partnership

Symptoms

System	Symptom
Respiratory	Breathlessness Cough
Cardiovascular	Chest tightness Chest pain Palpitations
General	Fatigue Fever Pain
Neurological	Cognitive Impairment Headache Sleep disturbance Peripheral Neuropathy Dizziness Delirium

System	Symptoms
Musculoskeletal	Joint pain Muscle pain
Psychological/psychological	Symptoms of depression Symptoms of anxiety
Ear, Nose, Throat symptoms	Tinnitus Earache Sore throat Dizziness Loss of taste/smell
Dermatological Symptoms	Skin rashes
Gastrointestinal	Abdominal Pain Nausea Diarrhoea Anorexia and reduced appetite

North East London Health & Care Partnership

Red flags

- Exclude other underlying pathologies
- Chest pain in someone with CVD risk factors
- Deteriorating breathlessness
- Hypoxia <94%
- Oxygen desaturation on exertion - fall of <3%
- Confusion
- Sudden onset/progressive memory impairment
- Focal weakness/neurology
- Significant Weight loss
- One symptom only – very unusual in long covid

Case study

- 87 F Caucasian
- Acute COVID 10/52 ago.
- 10/7 - worsening right calf swelling/tenderness.
- Progressive breathless for the last week and generalised myalgia.
- O/E - Saturations 95% on room air, Normal Resp exam.
- Swollen/Tender Right Calf – awaiting review in ?DVT clinic.
- PMH of chronic back pains from OA
- Needs exclusion of DVT/PE to ensure safe for rehab and exclude alternate cause of symptoms. (subsequently confirmed)

♂

North East London Health & Care Partnership

- 64 M Afro-Caribbean,
- Acute COVID Dec 2020.
- Seen via TC in Primary Care.
- Referred Sept 2021 – Progressive fatigue, Intermittent sternal discomfort, breathless
- “read about Long COVID and thinks symptoms fit”
- FH of IHD – mother died in 40s.
- PMH/SH - High cholesterol and smoker.
- Pro-BNP – 1449ng/L (0-400ng/l)
- New renal impairment - Creat 120umol/L
- Diverted to Heart Failure Service - Mod-Severe LVF diagnosed with abnormal ECG - Q waves

Case study

North East London Health & Care Partnership

- 39 F Caucasian
- COVID 4 months before referral
- Previously fit and well – Ran long distance.
- HPC: Breathless on exertion/bending/tying shoelaces, Fatigue, Fuzzy head. Generalise myalgia, occasional headaches and palpitations. Mild hair loss noted. Low in mood due to symptoms. Unable to look after children as easily due to symptoms
- Normal clinical examinations. Normal PEFR, Saturations and postural observations.
- Normal CXR, Normal TFTs, HbA1C, FBC, UEs, B12, LFTs, Bone profile.
- Mild Vitamin D deficiency.

- Requires
- – Review of cause of breathless, fatigue management and emotional/mental health support and neurocognitive assessment.
- - Vitamin D replacement

Next session/future webinars

North East London Health & Care Partnership

Date	Session Title	Speaker
8th March 2022 (1-2pm)	How to Assess & diagnose Long COVID; including what investigations to do	Dr Adam Ainley Consultant Respiratory Physician
5th April 2022 (1-2pm)	The Multidisciplinary Team Management of Long COVID Including social prescribing	Stephanie Poulton CoRe Service Lead
10th May (1-2pm)	Self-management strategies for Long COVID, including non-clinical pathways	Andrew Cook (ELFT Service Lead) Dr Chetna Patel (GP ELFT)
7th June (1-2pm)	Patient Case Studies: Examples from the NEL Long COVID Clinics	Representatives from each long COVID service

North East London Health & Care Partnership

Resources

- https://www.pulsetoday.co.uk/covid-19-primary-care-resources/guides/testing-trials-and-research/management-of-long-covid-in-primary-care
- Lopez-Leon, S., Wegman-Ostrosky, T., Perelman, C. et al. More than 50 long-term effects of COVID-19: a systematic review and meta-analysis. Sci Rep 11, 16144 (2021). https://doi.org/10.1038/s41598-021-95565-8
- Report template - NHSI website (england.nhs.uk)
- Dennis A, Wamil M, Alberts J On behalf of COVERSCAN study investigators*, et al* Multiorgan impairment in low-risk individuals with post-COVID-19 syndrome: a prospective, community-based study *BMJ Open* 2021;**11:**e048391. doi: 10.1136/bmjopen-2020-048391
- Yong SJ. Long COVID or post-COVID-19 syndrome: putative pathophysiology, risk factors, and treatments. Infect Dis (Lond). 2021;53(10):737-754. doi:10.1080/23744235.2021.1924397
- Ortona E, Malorni W. Long COVID: to investigate immunological mechanisms and sex/gender related aspects as fundamental steps for tailored therapy. Eur Respir J 2022; 59: 2102245 [DOI: 10.1183/13993003.02245-2021]
- Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK - Office for National Statistics (ons.gov.uk)
- Stephen, T et al. (2021) Long COVID - the physical and mental health of children and non-hospitalised young people 3 months after SARS-CoV-2 infection; a national matched cohort study (The CLoCk) Study (Pre-Print) Accessed at: Long COVID - the physical and mental health of children and non-hospitalised young people 3 months after SARS-CoV-2 infection; a national matched cohort study (The CLoCk) Study. | Research Square
- Long Covid Kids | Registered Charity | Post Covid Syndrome
- Managing the long-term effects of COVID-19 (sign.ac.uk)

North East London Health & Care Partnership

Questions and Feedback

Thank You

North East London Health & Care Partnership

North East London Health and Care Partnership is our integrated care system, which brings together NHS organisations, local authorities, community organisations and local people to ensure our residents can live healthier, happier lives.

www.northeastlondonhcp.nhs.uk | Follow us on Twitter @nelhcp

North East London Health and Care Partnership Citizen's Panel

Join our Citizen's Panel and help us shape health services in north east London.
Help create services that work for you and others in your area and get your voice heard.
enquiries@northeastlondonhcp.nhs.uk